

STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN

by

MARYNA SUSANNA GROBBELAAR

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SUPERVISOR: DR E KOTZÉ

JOINT SUPERVISOR: PROF. D J KOTZÉ


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0001943751

Student number: 3300-178-2

I declare that "stories of mothers with differently abled children" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

  
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(MRS MS GROBBELAAR)

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## **ABSTRACT**

A group of eight mothers of differently abled children undertook a research journey, reflecting on the sorrow and pain, as well as the hope and humour of our lives. Narrative pastoral practices guided our conversations, and prophetic and political challenges our actions to bring about change in our lived reality.

Reflective and summarising letters after each group meeting played a central part in the research. The letters were structured to make visible the “taken-for-granted truths”, which informed us about who and what we are. The alternative stories of preferred mothering practices that emerged during and between sessions were centralised in the letters. The group compiled letters of appeal to the faith community, doctors, nursing staff, therapists and teachers in order to make them more sensitive towards differently abled people and their families.

### **Key words:**

Motherhood; Mother blaming; Differently abled; Ableism; Participatory research; Narrative pastoral practices; Witnessing; Doing hope; Participatory ethical care; Prophetic ministry; Practical theology as a form of political theology

## PREFACE

Firstly, I would like to dedicate this research firstly to my son, Henk. Thank you for teaching me to appreciate the special qualities of differently abled people, and for opening my eyes to the "crime" of ableism. You taught me that "disabled" people are not *dis*-abled, but *differently*-abled.

Secondly, I would like to dedicate this research to the seven women who shared their stories of mothering differently abled children in the group sessions. It was a privilege to co-research with you, and to witness your sorrow and pain, as well as the golden thread of humour and hope of your lives. Thank you for the change that I experienced through sharing in your stories.

I would like to express my sincere appreciation to all the people who contributed to this research:

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If I may borrow Brueggemann's (1984:13) idea: the two of you are like a tree planted by streams of water (Ps 1:3). And I am better for it and blessed by it.

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# STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN

## CHAPTER 1: INTRODUCTION

As background to this study, I drew on my experience as the mother of a son with a severe stutter. I used this experience to outline the need of mothers with differently abled children to be cared for and to have their voices heard; to create a community of concern where they would be able to question and deconstruct the discourses that silence their voices; and to create the opportunity to re-tell their alternative preferred mothering stories.

### 1.1 THE INSPIRATION TO THE STUDY

I borrowed the term "differently abled" from Reinhartz (1992:193) to describe the persons that I refer to in this study. Other terms that I considered, were "specially abled" children borrowed from David Epston (Freeman, Epston & Lobovits 1997:182), and "weirdly abled", the alternative Epston also uses. During the study, the terminology to be used was negotiated with the participants. Apart from the terms mentioned above, the following terms were suggested: "disabled", "handicapped", "children with disabilities", "children with special needs", "physically challenged children". The group decided that we wanted to concentrate on the things our children are able to do, rather than those things they have difficulties with. We therefore preferred the term "differently abled". This term was also descriptive and included all the different abilities that were represented in the group. (See chapter 3 for an introduction of the participants.)

I believe that the term "differently abled" is on target when I describe my fifteen-year-old son who has a severe stutter. This is how he wanted to introduce himself:

Hi there! My name is Henk. I am fifteen years old, and I stutter. Like in BAD. My mom and aunts always tell me that I am very handsome – well, I am tall and lean with blue eyes, and I regularly work out in the gym to work on my "six pack". There are a few girls trying to get my attention (unfortunately not the ones I would like to), but I think the old ladies overdo things a little. I am also blessed with an even, likeable temperament. The older women in the family call me charming. In short, people tend to like me.

Look, I know that I am not perfect. And I can assure you that life as a stutterer is not always moonlight and roses. But things are not that bad. I can talk confidently to anybody, even strangers,

because I know that I am not the kind of person who will put someone else down. I believe that people respect me for my self-confidence.

The grossest thing of all is when people do not have the patience to give me time to complete my sentences. Look, I know that even I become impatient with myself sometimes – like the time I tried to warn my mother she was going to bump into the car in front of hers and I only got the warning out the same moment that the two cars collided – but please, is it too much to ask just to keep quiet and give me a chance?

On the other hand there are the people who pity me and who do not treat me the same as anybody else. Oh please! What do you people think! However, sometimes it suits me fine. Like when I do not prepare for an oral. Then it is easy to convince the teacher (unfortunately only some of them) that I cannot make a speech that day.

Another thing that makes me really angry is people making fun of others who are different from them.

In a funny way, I am grateful for the way I am. I believe that because I had to learn to cope with stuttering from very early on, it helped me to learn to handle a lot of other issues. Things that my friends make a big deal of do not matter that much to me. Perhaps I have learned that nobody is perfect anyway, and nobody is better than anybody else.

As the mother of a differently abled child, I had to embark on what I can only call an “emotional marathon”.

At first, I was trying to “fix” my son. I wanted him to fit into the “box” I had created for him according to the idealised notion of what I believed he should be. My cultural background and the way I was brought up, as well as my baggage of discourses, played a dominant role in designing this “box”. In an attempt to “fix” my son, I travelled a long and difficult road. In retrospect, I am not sure which one of us suffered most: Henk, trying to become someone I wanted him to be, but could not be, or I, believing that if I failed to “fix” him, I failed as a mother. We consulted almost the whole spectrum of therapists, starting at a Child Guidance Clinic, moving on to the first of several speech therapists, an occupational therapist, a child psychologist and a clinical psychologist, followed by a family therapist. I was referred to therapists by other therapists. Sometimes I questioned the sense and relevance of all these therapies, but also believed that if I did not follow up on the advice of the therapist, I could be labelled as a bad mother, resisting change.

After a very long and difficult journey on this path, I finally realised that only my husband, my son and I could decide what was best for him and for us. And the best was to accept him the way he was. For me, this was to a certain extent like an obstacle course in this emotional marathon I was bound to complete. Painfully and slowly I found my voice to story my experience and to identify obstacles in my way.

In my mind all the different (and sometimes conflicting) ideas from my own background, my husband's background, the school system, my love for my child, my expectations for his future, demands from society and demands from the different therapists that I had consulted, were competing for the privileged or central position. More than once I felt like Ben Uil, the character with schizophrenia in *Duiwelskloof*, André P Brink's novel. The schizophrenic voices spoke so loud that he could be heard approaching from a distance and nobody was able to have a meaningful conversation with him around (Brink 1998:110, 228).

I found the advice offered in the vast variety of books and guides on parenting quite inadequate. For example: Dr James Dobson (1987:87), the popular Christian psychologist, simply advises parents with what he calls a "strong-willed" child, to "take the child God sends to you and 'go with the flow'". To parents who have difficulty accepting the child the way she/he is, his advice is equally simple: (a) "Vent those feelings to your husband, wife or close friend" and (b) "determine to love the child come what may" (Dobson 1987:87). I struggled with this advice, as I could not figure out why it was so difficult for me to accomplish what was offered in such a matter of fact tone – it was supposed to be so easy! This only contributed to my feelings of inadequacy – I felt all the more a failure as a mother.

As a white, middle-class Afrikaans-speaking woman in a predominantly patriarchal society, I had no choice but to accept the role of the "mothering person" (Sevenhuijsen 1998:11) even though I felt that I was not equipped for the "job". Trapped in a jungle of discourses I felt so paralysed that I needed help to free myself from the restrictions imposed by cultural discourses.

In my experience, professionals like speech therapists, occupational therapists, teachers or child psychologists were no more helpful. On the contrary, in most cases they added to my personal dilemma of experiencing myself as an inadequate mother. Somehow I managed to blame myself for the lack of positive results of especially the speech therapies. At times I actually felt totally powerless. I later identified these as mother-blaming discourses.

Weingarten (1998:3) refers to the pervasive practice of mother blaming and the ubiquitous splitting of mothers and mothering into good and bad, right and wrong that underlies it. She refers to a study into the incidence of mother blaming in major clinical journals in three target years (1970, 1976 and 1982) and notes that mothers were blamed for a total of seventy-two different forms of psychopathology that their children suffered.

From personal experience, I agree with Hoffman (1990:9) when she questions Batesonian systemic concepts by saying that the therapist is operating from an alien set of assumptions. She is of the opinion that "most of these assumptions ... are blaming and judgmental".

Bosch (1991:484) uses the terminology "haves" and "have nots". Although he uses this terminology in a spiritual sense, suggesting that Christians "are not the 'haves', the *beati possidentes*, standing over against spiritual 'have nots', the *massa damnata*", it was a good description of the way I felt – the professionals were the "haves" and I was the "have not".

The well-meant advice and comments from family and friends did not help either. The advice ranged from accusing me of doing too much, like overprotecting my child, to referring me to an exorcist in order to drive out the evil spirit that was possessing my son, causing the stutter. All this added to my feeling that there was something wrong with my son and that it had to be "fixed". I now recognise it as the discourse of "ableism" (Reinharz 1992:258).

Being a religious person, my dilemma became a faith issue as well. I went through the whole spectrum of asking "Why me?", to self-doubt – if I were a good enough Christian, why did God not answer my prayers and heal my son, to eventual acceptance of the cards I was dealt (Weingarten 2000a) to make the best I could of the situation.

The advice we received from therapists was focused on our son, and we, the parents, were only guided to understand our child better and how to cope with the situation. My inner struggle went by unrecognised. I felt that I did not have a voice. I did not speak out because of my fear to be judged as an incompetent or non-compliant mother.

Features, fiction, advertisements and advice columns in women's magazines all focus on how women may best negotiate their familial roles. "As ... mothers we are encouraged to accommodate ourselves to families at the expense of our own feelings and the quality of our lives" (Weedon 1987:38). In my case, I first failed

to "fix" my son, and then I failed to accept him the way he was. I became so sensitive to the idea of failure, that even the lift of an eyebrow from a friend was enough to silence my voice.

According to Greenspan (1998:38), mothers of differently abled children find themselves being marginalised because of perceptions of difference, as well as "largely being socially invisible, an invisibility that is both part of and distinct from the social invisibility of people with disability themselves. We just don't exist. Where are we? And what are we doing?"

## **1.2 MY COMMITMENT IN THIS STUDY**

Since I have learnt a language to describe what I experience as the mother of a differently abled child, I formed a habit of telling my story to other mothers that are in more or less the same situation. In any group where mothers gathered, be it housewives in a Bible study group or a gathering of professional women, at least one, but mostly two or more mothers, indicated that they resonated with my story.

I experienced the desire to introduce these mothers to a discourse that would enable them to see how they are situated by these discourses and story lines that constitute motherhood. I wanted them to identify the cultural and historical production of motherhood in which we can become stuck and marginalised. I wanted to introduce mothers to the possibility of becoming producers of their own culture – we do not have to "be mesmerised by the great lament of contemporary culture" (White 1997:222). I wanted them to explore the "ways in which identity, subjectivity, and relationship are all products of cultural knowledges and practices" (White 1997:223), and to recognise the interaction between themselves as fictions and the fiction of their culture which is constantly being (re)spoken, (re)written and (re)lived (Davies 1993:2). I wanted each mother to discover her preferred identity as a mother of a child with different abilities. This became my commitment embodied in this study.

Through the telling of their stories, I wanted the mothers to enable themselves to rediscover their preferred identities as mothers, to develop their own preferred mothering practices – the "reclaiming [of] one's history is an important step in understanding and learning to celebrate one's identity .... Reclaiming that history is important in enabling people to set their lives in a broader context and to comprehend them; it is a step towards empowerment" (Walmsley 1995:72).

My hope was that within this process, mothers as participants of the study would be enabled to share in a deconstruction of dominant discourses such as ableism and mothering.

Greenspan (1998:38) mentions how a mother (and a family) of a child with different abilities, is shunted to the outer edges of the social mainstream, how she experiences radical isolation, and yet she also has "the possibility of a 'different' view of the center, a different view of family life, motherhood, and personhood that is both subversive and liberating".

Apart from my commitment to the mothers' benefit, I entertained more questions while formulating my commitment: would I be able to make a contribution to the field of practical theology and pastoral praxis in co-searching its responsibility to a small part of its community? How would pastoral therapists benefit from the collecting of narratives co-constructed by the mothers of differently abled children? Would the research be able to assist us in deconstructing (Sampson 1989; White 1991; Wolfreys 1998) dominant discourses of ableism and mothering?

Would this research contribute to taking a step towards ethical ways of research? How will the community, faith community or society benefit from this research? How would the differently abled children eventually benefit? How would the children and young people experience our group discussions regarding our mothering practices? How could we be respectful of their voices and ideas on being differently abled? In view of what inspired me and the commitment I made I present my "research curiosity"<sup>1</sup>.

### **1.3 RESEARCH CURIOSITY**

Inspired by finding a voice to story my own experiences, I became curious about how mothers:

- story their experiences (and themselves through these experiences) of being a mother of a differently abled child;
- deconstruct dominant discourses constituting the mothering of their differently abled child; and
- story their "not yet said" (Anderson & Goolishian 1988) mothering practices.

I formulated these curiosities before engaging in conversations with the participating mothers.

### **1.4 PURPOSE OF THE STUDY**

I was committed to facilitate mothers to question the reproduction and maintenance of dominant mothering discourses. I believed that the process of deconstructing these discourses could empower mothers to confront and to interrogate these discourses, enabling them to decide whether they are going to accept,

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<sup>1</sup> "Research curiosity" is preferred in place of terminology such as "research question" or "research problem".

change or discard the discourses; enabling them to make an informed decision, to no longer be ruled on an "unconscious level" (Weingarten 2000a).

My purpose with this study was to gather a group of five to eight mothers of differently abled children who were inspired by a desire to talk about experiences and mothering practices. Informed by my research curiosity, I formulated the following aims for the study:

- To explore with the participants the influence of socially constructed discourses regarding motherhood, special abilities, special needs and disability on people's lives, focusing on mothers of differently abled children and how these discourses have affected/informed them.
- To explore with the participants the discourses and/or power/knowledge relations influencing the parent/professional relationship.
- To co-construct alternative stories, deconstructing the dominant discourses and to re-tell the preferred mothering stories.

Following a power-sharing model (Bishop 1996), my further purpose was to discuss with this group my research curiosities, as well as theirs, upon which to negotiate the aims we would want to set for our journey together. My purpose with these negotiations was to ensure "[a]uthentic participation", which "means sharing in the way research is conceptualized, practised, and brought to bear on the lifeworld" (McTaggart 1997:6). In creating co-ownership of the study I aimed at counteracting a "mere involvement" or "co-opting" (McTaggart 1997:6) of participants. I realised that this could eventually lead to changing my initial commitment and curiosity that inspired this study.

From the first session it was apparent that what the participants wanted, was witnesses to their stories. As I was committed to authentic participation, and determined to follow an approach of power sharing and narrative free-ranging conversations where the participants help set the agenda, the emphasis of the study shifted more towards listening to their stories, and creating a platform where they could vent their feelings and make their voices heard. I therefore refrained from introducing topics for discussion. They just started talking and kept on talking way past the hour and a half we had planned for the sessions. The participants had never before had the opportunity to say what had been bottled up for so long.

I was not prepared for the tension between my commitment to authentic participation and my own political/ethical position or agenda that I was pushing. I had to remind myself of the idea of capitalism as introduced by Bosch (1979:31) when he warned against the influence of capitalism, in the sense that in everything we undertake we think in the categories of success, yield and dividends. The result is that we

"feel terribly embarrassed when we cannot report tangible results". I recognised my "fear for embarrassment" that the outcome of the research would fail to produce tangible results if I do not come up with answers to all the questions I posed at the onset of the research.

I also referred myself to the ideas of Wright, Watson and Bell (1996:161) that families find therapists' invitations to engage in meaningful conversations about the impact of illness on their lives to be one of the most useful interventions in assisting families to move beyond and overcoming problems. "The capacity of clinicians to be 'witnesses' to the stories of suffering of patients and families is central to providing care; it is frequently the genesis of healing, if not curing" (Wright, Watson & Bell 1996:161).

## **1.5 DISCURSIVE POSITIONING<sup>2</sup>**

In this section I will introduce the discursive positioning that will form the broad conceptual context for this study. Within this context, I will indicate how a feminist theology of praxis guided the process of pastoral care that was practised in this study.

In a postmodern paradigm there is an emerging body of knowledge that argues that "reality can never be fully apprehended, only approximated" (Denzin & Lincoln 1994:5). Geertz defines the analysis of human action as an "interpretive science in search of meaning, not an experimental science in search of laws" (quoted by Schwandt 1994:122). Lather (1991:53) argues for the "development of a change enhancing, interactive, contextualized approach to knowledge-building ... that is provocative in theory and ... method".

True to this paradigm, a number of alternative ways of investigating and understanding in the social sciences have emerged. The telling of stories has become a valuable way of documenting research: "[S]tories are as important, relevant, valid, reliable, meaningful and generalisable as any other writing that is referred to as research" (Ballard 1994:22).

Emancipatory social research also "offers a powerful opportunity for praxis to the extent that it enables people to change by encouraging self-reflection and a deeper understanding of their particular situations" (Lather 1991:56).

Based mainly on these assumptions and practices, I prefer a qualitative approach to research for the purpose of this study. Qualitative research implies

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<sup>2</sup> See Davies, B. & Harré, R. 1990. Positioning: the discursive production of selves.



an emphasis on processes and meaning that are not rigorously examined, or measured (if measured at all), in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning.

(Denzin & Lincoln 1994:4)

The meaning of any experience will depend on the struggle over the interpretation and definition of that experience. I understand that "individual identity and human agency form such a chaotic knot of intertwined articulations that no social theorist can ever completely disentangle them" (Kincheloe & McLaren 1994:146). Kincheloe and McLaren (1994:140) also refer to Foucault, inviting researchers to explore the ways in which discourses are implicated in relations of power, and how power and knowledge serve as dialectically reinitiating practices that regulate what is considered reasonable and true.

This study attempted to open up an understanding of the experiences of mothers of differently abled children. Stories told by the mothers presented pictures of their experiences and of the contexts that reflect actual, lived experiences rather than the predetermined categories of experiences that a researcher may think, possibly erroneously, are important. Through the telling of their stories the mothers made their voices heard. This participatory knowledge would assist to "displace subjective beliefs in objectivity and 'quantitative mysticism' that have dominated social science for too long" (Ballard 1994:314).

Mothers of differently abled children were introduced to the possibility of not being passive recipients of the discourses induced on them through their culture, but to rewrite their own preferred life stories. In the words of Lather (1991:63), "[t]he present is cast against a historical background while at the same time the 'naturalness' of social arrangements is challenged so that social actors can see both the constraints and the potential for change in their situations".

In this sense, I believe that to engage in qualitative research is to take part in "pragmatics of hope in an age of cynical reason" (Kincheloe & McLaren 1994:154).

Hence, the emphasis in this study was not on my own observations and interpretations, but on the meanings generated by the mothers who shared their experiences in the stories they told. I was not "an independent observer but rather an inter-dependant participant within the meaning-generating system" (Botha 1998:82).

In feminist research it is a common consequence that the research changes the researcher. Many feminist researchers report being profoundly changed by what they learned about themselves. Changes that researchers undergo may involve completely reconceptualising a phenomenon and completely revising one's worldview, or it may lead to harsh recognition of one's own shortcomings. Some researchers discover that their research has sustained their lives. The least that we as researchers should expect is to "clarify our vision and improve our decisions" (Reinharz 1992:195).

## **1.6 PASTORAL CARE IN THE FRAMEWORK OF A FEMINIST THEOLOGY OF PRAXIS**

Theology does not "only rely on the contemporary discourses in any culture for its construction, it is also an activity that reflects on the meaning of the Scriptures for contemporary culture" (Botha 1998:125). Therefore, theology is not a "timeless and a closed system of theological knowledge, unaffected by cultural shifts" (Rossouw 1993:895). "Pastoral Theology is more like living water than a tablet of stone. It is something that moves and changes shape, content and appearance, like a lake, over time" (Pattison quoted by Graham 1996:56).

### **1.6.1 A feminist theology of praxis**

A feminist theology of praxis arises from the need to reflect on Christian praxes in specific contexts for the sake of a better and more adequate praxis mediated through changed theories. A feminist theology of praxis is based on the transformed consciousness of seeing things "from the outer circles" (Ackermann 1996:42). Feminist theology takes as its starting point the experiences of women and men and their interaction with each other and with society as "a source from which to do theology" (Isherwood & McEwan 1993:35). Feminist theology learned from liberation theology that we cannot do theology "as though we lived in some abstract realm or dead corner of history – we have to be involved in our world .... [I]njustice is not simply an act of fate; it is caused by people's actions and therefore requires people's actions to redress the balance" (Isherwood & McEwan 1993:76).

Belief in the role of human agency in the "mending of God's creation" (Ackermann 1996:34) lies at the heart of a feminist practical theological insistence on just, healing and liberating praxes. The mending of creation speaks of justice, love, freedom, equality and the flourishing of righteousness, all of which foster good relations between and among people (Ackermann 1996:47). The ethical task of feminist theology is to "develop our capacity for love and loving" (Isherwood & McEwan 1993:70). When it is connected with our becoming or our concern for the becoming of others, love "manifest[s] as a commitment to justice in the world" (Isherwood & McEwan 1993:70). The quest for theological reflection will no longer ask the question "is something Christian?" but "is something healthy?" (Isherwood & McEwan 1993:86).

For the purpose of this study, in order to explore the influence of social constructed discourses on the lives of mothers with differently abled children and on differently abled people in the broader society, I chose a feminist theology of praxis as epistemology. I believe that this paradigm was the most appropriate to meet the aims of the study.

### **1.6.2 Pastoral care**

Sevenhuijsen (1998:131) describes care as the "repairing of citizens so that they can once more take part in their normal social participation". In a pastoral therapeutic dialogue, a theological tradition can function, through language, as "a participant in a dialogue" (Pieterse 1993:81), which means that the "story of God, becomes a conversational partner" (Botha 1998:160). We can treat the great story of God, i.e. our theological tradition, as another cultural discourse that participates in the conversation.

In this "battle of discourses" (Botha 1998:161), the pastoral therapist has the responsibility to facilitate the maintenance and further development of the person's spiritual or faith story and the dialogue with its tradition on the one hand, and to facilitate the growth and creative development of particular life stories, on the other hand (Gerkin 1997:113).

I believe that by exploring the influence of cultural discourses on the construction of the stories of mothers with differently abled children and by co-constructing their preferred stories, ignorance of the discourses connected to the mothers' spirituality could result in incomplete preferred stories. I wanted to open conversations for the "most significant conversations to be heard and understood, and for the most significant others to be included in the construction of meaning, even when the significant other may be the Other, who is known by many names, whom some call God" (Griffith 1995:124).

The relational dimension of care, however, has more implications as Bauman's version of Foucault's concept of pastoral power indicates. Bauman (quoted by Sevenhuijsen 1998:18) labels care for the other and love motives as "one of the most insidious of the many shapes of domination, as it blackmails its object into obedience". If the specific needs of the receiver of the care are disregarded, "we run the risk of ending up in a position of moral arrogance" (Sevenhuijsen 1998:140). Therefore, we should rather

think about the way social practices give rise to certain attitudes and moral frameworks, and vice versa ... and to adapt our judgements about care politics to the fact that power and conflict are involved in every phase of the caring process .... Deliberations about what constitutes necessary care are structured by power and depend upon the position from which one speaks.  
(Sevenhuijsen 1998:138)

## **1.7 TRUSTWORTHINESS OF THE RESEARCH AS CARE**

In an epistemology of qualitative research, the possibility of objectivity is no longer seen "as a life option" resulting in an attempt to "manage subjectivity". Heshusius (1994:15) suggests that "if we want to free ourselves from objectivity we need to ... turn toward a participatory mode of consciousness". A participatory mode of consciousness results from the ability to temporarily let go of all preoccupation with the self and move into a state of complete attention. It reflects a holistic epistemology that replaces the traditional relation between truth and interpretation in which the idea of truth antedates the idea of interpretation. The issue is not to define levels of completeness of merging, or of interpretation, but to foster a participatory quality of attention. "[P]articipatory consciousness [is] not autobiographical, as the attempt to account for one's subjectivity can so readily become. What is seen as subjectivity is about one's own life. About one's past .... Participatory consciousness [is] not 'about' something or someone; [it refers] to 'being with' something or someone" (Heshusius 1994:19). In this sense this research is care.

In view of the above, it was not my intention to search for some magic method of inquiry that would guarantee the validity of the findings of this study. I kept in mind though, the criteria to assess the trustworthiness of qualitative research as suggested by Kincheloe and McLaren (1994:151):

- Qualitative researchers do not believe that research descriptions can portray "reality" accurately. They reward credibility only when constructions are plausible to those who constructed them – the participants.
- Qualitative researchers question external validity, arguing that this traditionalist concept of external validation is too simplistic. Instead, Piaget's notion of accommodation seems more appropriate in this context, as it asserts that humans reshape cognitive structures to accommodate unique aspects of what they perceive in new contexts.
- Qualitative researchers advocate catalytic validity, which points to the degree that research moves those that it studies to understand the world and the way it is shaped in order for them to transform it. The research should display the reality altering impact of the inquiry process, so that those under study will gain self-understanding and self-direction.

## **1.8 REPORT FORMAT**

Reinharz (1992:211) explains how feminist researchers, embarking on important research projects, are like people setting out on important journeys. Feminist research tends to be written in a way that reveals the process of discovering and journeying. The report format of the study was influenced by the participants and is presented in a process format since the process became part of the product (Reinharz 1992:212).

I wanted the participants to take part in the presentation of the research report and suggested a conversation format because single-authored writing smoothes out controversy and silences voices, but “[c]onversations are harder to read because the reader has to take part, and work out the differences, in single-voiced writings, readers can simply sit back and ‘listen’ to the voices of authority” (Reinharz 1992:231). My hope for the research report echoes Denzin's (1994:512) comments on how postmodern researchers attempt “to produce reader-friendly, multivoiced texts that speak to the worlds of lived experience”.

As feminism aims to transform competitive and exploitative relations among women into bonds of solidarity and mutuality (not denying diversity/plurality), I hope that the research, as well as the report, will mirror these aims.

## **1.9 CHAPTER OUTLINE**

An outline of the content and context of the research report follows:

Chapter two focuses on ideas on the social construction of motherhood and ableism in the society.

Chapter three gives an outline of the research journey, and an introduction of the participants.

Chapter four describes the group meetings through the reflective letters and illustrates how the narrative process was used to externalise the discourses informing the participants, the effect on their mothering practices, and the thin descriptions they have formed of themselves as mothers.

Chapter five focuses on pastoral care for families with differently abled children. It also touches on “doing theology”, describing the action the group initiated in order to bring about a change in the situation of all differently abled people and their families.

Chapter six reflects on the research project. Recommendations for practical theology and pastoral therapy are also offered.

## CHAPTER 2: DECONSTRUCTING THE MYTHS OF MOTHERHOOD AND ABLEISM

### 2.1 INTRODUCTION

*Paris 1780: 21 000 babies were born in Paris in 1780  
1 000 were breast-fed by their mothers  
1 000 were breast-fed by live-in wet nurses  
19 000 were taken from their mothers and sent away to wet nurses, mostly outside Paris  
(Badinter 1980:xix).*

*Between five and fifteen percent of the babies died on their trip to the nurses (Badinter 1980:95). The nurses themselves lived in pathetic conditions. They were incredibly poor, and were forced to work in the fields, spending the better part of the day away from their cottages. The children were "left to themselves, drowning in their own excrement, bound like a criminal, devoured by mosquitoes ....The milk he sucks is a milk overheated by strenuous exercise, a bitter, watery, yellowish milk.. And in addition the most frightening accidents put them within an inch of the grave" (Gilbert quoted by Badinter 1980:95).*

*Once the baby was left in the nurse's hands, the parents lost interest in his fate. Four years was the average length of the child's stay with the nurse. "When the child returned home – if he returned – he was often crippled, rachitic or sick. The parents would complain bitterly and perhaps more noisily than if their child had died – because a child in poor health meant many future expenses and few long-term benefits" (Badinter 1980:99).*

*Paris 1980: Deutsch (quoted by Badinter 1980:272) defines the good mother as "the feminine woman' constituted by the harmonious interaction of narcissistic tendencies and the masochistic capability to tolerate suffering". She continues by saying, "Praised be nature's wisdom in creating women a being whose love for her child is 'normally greater than her self-love'" (Badinter 1980:273).*

One may ask how this discrepancy in the description of interest in and devotion to children over a period of two hundred years can be accounted for? I believe that the cue can be found in the way people socially construct meaning - in this instance, motherhood.

## **2.2 SOCIAL CONSTRUCTION DISCOURSE**

The social construction discourse is concerned with “explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live” (Gergen 1985:266). It approaches knowledge from the perspective of the social processes through which it is created. Knowledge is not viewed as the objective reflection or representation of an external reality, but as the social construction of people in their attempt to live together in this world (Freedman & Combs 1996). It is through the “daily interactions between people in the course of social life that our versions of knowledge become fabricated” (Burr 1995:4).

Meanings are co-created and experienced by individuals in conversation with one another. “People live, and understand their living, through socially constructed narrative realities that give meaning and organization to their experience” (Anderson & Goolishian 1992:26). According to Anderson (1997:41), “everything is authored, or more precisely, multiauthored, in a community of persons and relationships. The meanings...that we attribute to the things, the events, and the people in our lives, and to ourselves, are arrived at by the language people use – through social dialogue, interchange, and interaction that we socially construct”. It is an active, creative task, and is a “setting for imaginative, creative speech that forms new worlds for us” (Brueggemann 1984:10).

Therefore, understanding is “linguistically, historically, and culturally situated” (Anderson 1997:39). The ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific – it “depends upon where and when in the world one lives .... they are seen as products of that culture and history” (Burr 1995:4).

Social constructionism moves beyond the social contextualisation of behaviour. Context is thought of as a “multirelational and linguistic domain in which behavior, feelings, emotions, and understandings are communal. They occur within a plurality of ever-changing, complex webs of relationships and social processes, and within local and broader linguistic domains/practices/discourses” (Anderson 1997:44).

## **2.3 THE CONCEPT OF DISCOURSE**

There is always a broader social context that constitutes or shapes the stories of our lives, that influences the interpretations and meanings we give to our experiences. This broader social context, or discourse, is a network of statements, practices and institutional structures that share common values. Foucault refers to discourse as a “regime of truth”, which should be understood as “a system of ordered procedures for the production, regulation, distribution, circulation, and operation of statements .... [It] is linked in a circular

relation with systems of power which produce and sustain it, and to effects of power which it induces and which extends it" (Rabinow 1984:74).

Discourse "includes both linguistic and non-linguistic aspects; it is the medium that provides the words and ideas for speech, as well as the cultural practices involving related concepts and behaviors .... By a restrictive and expressive set of codes and conventions, discourses sustain a certain worldview .... [D]iscourses do not simply describe the social world; they also categorize it. In so doing, discourses bring certain phenomena into sight and obscure other phenomena. The way most people in a society hold, talk about, and act on a common, shared viewpoint are part of and sustain the prevailing discourses" (Hare-Mustin 1994:19-20).

Discourse theory suggests that "we do not develop meaning out of a void, but out of a pre-existing, shared language, and through discursive practices that reflect and reenact the traditions, power relations, and institutions of the society" (Hare-Mustin 1994:23). The beliefs, ideas and practices of the culture in which we live, or "taken-for-granted realities and practices" (White 1991:27), play a major part in the meanings we make of our lives. Discourses "powerfully shape a person's choices about what life events can be storied and how they should be storied" (Freedman & Combs 1996:43). Discourses are perceived as "truths" or "common sense", influencing our understanding of the way life is or should be (Gerkin 1991:54).

These discourses are mostly invisible. Just as we "disattend the pane of glass in order to look at the view out the window, so we generally disattend discourse. It is not until the glass fractures or breaks, for example, that we focus differently" (Davies1993:153). Because discourse is transparent, any text that mobilises that discourse is taken to describe a real and recognisable world. For example, we accept the discourse of the mother as a caring, self-sacrificing individual as one of such "taken-for-granted ideas and practices" (White 1995:46), that one finds the lot of the babies of the eighteenth century as described at the beginning of this chapter, quite disturbing. Yet mothers then participated in those practices.

Discourses also shift in meaning according to context and to the positioning of the subjects within them, and are also often in tension, providing people with multiple layers of contradictory meanings that are inscribed in their bodies and in their minds. Lowe (1991) refers to alternative discourses, competing with one another, producing distinctly incompatible versions of reality.

In order to make these discourses available for "questioning and challenge" (Morgan 2000:45), they have to be pulled apart and examined (Morgan 2000:47) – they have to be deconstructed.



## 2.4 DECONSTRUCTION

Wolfeys (1998:23) cautions that "[w]hatever seems obvious, whatever appears as 'natural' or 'common-sensical', relies often on an immense body of knowledge and ways of thinking". Therefore, the dominant notion of a "text" has to be extended and expanded, because a text is always a "differential network, a fabric of traces referring endlessly to something other than itself, to other differential traces" (Derrida, quoted by Wolfeys 1998:18).

The approach to literary interpretation known as deconstruction, therefore denies that texts have a single fixed meaning. Deconstruction offers "a means of examining the way language operates below our everyday level of awareness to create meaning" (Hare-Mustin & Maracek 1988:460).

Deconstruction is, however, "not something we can lay out like the components of some engine in order to assemble a 'deconstruction-machine'" (Wolfeys 1998:15). Derrida (quoted by Wolfeys 1998:17) uses the metaphor of a dredging machine: as the teeth scrape the seabed, "random particles are picked up, while something is dropped, something remains and something cannot be scooped up in the first place".

To deconstruct is "to undo, not to destroy" (Sampson 1989:7). Sampson also refers to the notion of placing a term under erasure – *sous ratoure* – to accentuate that the term is both useful and necessary and not useful and wrong at the same time. Sampson contends that "[w]ithin the meaning of any possible text there is also its opposite text" (Sampson 1989:8). Therefore, to deconstruct a text, one should listen for what was not said; to "the opposite meaning within what was said, to validate and to question what was said and what was not said" (Sampson 1989:8).

Parker and Shotter (1990:4) refer to deconstruction as "not just to unravel hidden assumptions and to uncover repressed meanings, but to bring to the fore concerns altogether different from those implicated in the discourses concerned".

Morgan (2000:46) defines deconstruction as "[t]he pulling apart and examining of 'taken for granted' truths". By deconstructing conversations, the therapist examines these ideas and practices, defines them, pulls them apart and traces their history. Deconstruction can lead to the challenging of discourses and "open alternative stories that assist people to challenge and break from the problem's views and to be more connected with their own preferred ideas, thoughts and ways of living" (Morgan 2000:49).

## 2.5 THE SOCIAL CONSTRUCTION OF MOTHERHOOD

Maternal love has been discussed as a kind of instinct for so long, that a “maternal instinct” has become seemingly rooted in a woman’s nature, regardless of the time or place in which she lived. In the discourse of motherhood, every woman fulfils her destiny once she becomes a mother, finding within herself all required responses, as if they were automatic and inevitable, held in reserve to await the right moment. Because reproduction is a natural function, surely – or so it has been assumed according to common sense knowledge - the biological and physiological fact of pregnancy must carry with it “a corresponding battery of predetermined maternal attitudes and patterns of behaviour” (Badinter 1980:xx). When a woman becomes pregnant, one might imagine “that the resulting birth would *naturally* make her a mother” (Silva 1996:42). Even Christianity sometimes “equated female salvation with childbearing (1 Tim. 2:15) and defined women almost solely in terms of their destiny as mothers” (Treadway & Miller-McLemore 2000:176).

But as Gergen (1994:223) points out, “the vocabulary of the emotions and the patterns what Westerners call ‘emotional expression’ vary dramatically from one culture or historical period to another”. Therefore, “[m]aternal love is a feeling. And like any feeling, it is uncertain, fragile, and imperfect. Contrary to many assumptions, it is not a deeply rooted given in women’s natures. When we observe the historical changes in maternal behaviour, we notice that interest in and devotion to the child are sometimes in evidence, sometimes not. Affection may or may not be present” (Badinter 1980:xxiii). Feminist perspectives have asserted that “motherhood and mothering are not natural for women but that they are historically, culturally and socially constructed” (Silva 1996:1). Birth has not always led to mothering as we now understand the concept. The choices made by women were determined by the dominant values of the society in which they lived – by the prevailing dominant discourses and the ecology of resources and realities.

### 2.5.1 The genealogy of motherhood

According to Foucault (Rabinow 1984:59), one has to dispense with the constituent subject, in order to get rid of the subject itself, to arrive at an analysis which can account for the constitution of the subject within a historical framework. He refers to this process as “genealogy, that is, a form of history which can account for the constitution of knowledges, discourses, domains of objects”. Historically speaking there has been “such a heavy weight of machinery brought to bear on women to force them into motherhood we must ask why these measures were necessary if motherhood itself was simply a biological process like ageing” (Silva 1996:39). We therefore “need to expose the construction of dominant normative constraints that create certain categories of mothers as bad or inadequate because they are perceived to fail to live up to the ideals of motherhood that are imposed through legal and public policies” (Silva 1996:39).

To begin any deconstruction of motherhood, we have to go behind the supposedly natural chain of events that are presumed to be so natural as to be inevitable, unquestionable and automatic. "Rather than the unfolding of nature we can see a channelling of choices and options that are historically and culturally specific. At each stage of this process, decisions are taken that relate to existing values, social conditions and available options" (Silva 1996:39).

A short journey through the history of motherhood should illustrate how the discourses dictating the knowledge we have about motherhood and the behaviour that are deemed appropriate for mothers, differ over time. I will give a broad overview of three main periods: before the eighteenth century, eighteenth to nineteenth century and the twentieth century.

### **2.5.2 The absence of "love"**

The literature, philosophy and theology of the sixteenth century, educational practices, as well as statistics to our disposal, demonstrate how little the child counted within the family circle (Badinter 1980:56). Before the eighteenth century, chronicles written by theologians and other intellectuals showed such little interest in mothers, whether loving or "warped", that one is led to conclude that maternal love was not a social and moral value at that time. The privileged women, who chose not to tend to their children, did not have threats or guilt of any kind hanging over them. Writers (theologians and other intellectuals) of the late eighteenth century ironically noted with regard to the practices of sending babies to wet nurses for the first years of their lives, that "most people took greater pains in choosing a servant, a groom to care for their horses, or a cook" (Badinter 1980:94) than choosing a wet nurse to care for the baby. (It was only after the publication of *Emile* by Jean-Jacques Rousseau in 1762 that these theologians and other intellectuals became sensitive to the issue.)

During these times, the husband-father as head of the house ruled the family unit – he was its centre and everything should be arranged according to his needs. Badinter (1980:51) refers to Rétif de la Bretonne's grandmother who welcomed her son Edmè (Rétif's father) with sincere joy when he returned from a trip. She was, however, so concerned with her husband (Rétif's grandfather) that she sent her daughters to see to their brother, because "for me, here is my lot [her husband], whom I will surrender to no one, not even to my children".

Clearly motherhood was "not yet the 'fashion'" (Badinter 1980:60).

### 2.5.3 The birth of the myth of motherhood

It was in the last third of the eighteenth century that a radical change in thinking took place. "The image of the mother, of her role, and of her significance changed radically, although actual behaviour lagged behind" (Badinter 1980:117).

The modern family, characterised by an affection and closeness that binds parents to children, was born with the publication of *Emile* by Jean-Jacques Rousseau in 1762. He crystallised a new set of ideas of the family founded on maternal love.

After *Emile*, publications abounded advising mothers to take care of their children personally, and "ordering" them to breast-feed. "They created an atmosphere of obligation in which women were told to be mothers first and foremost, engendering a myth that is still tenaciously supported two hundred years later: maternal instinct, or the spontaneous love of all mothers for their children" (Badinter 1980:117).

At first, paternal authority had been highly emphasised because it was considered crucial to raise "docile bodies" (Foucault 1977:138) for His Majesty. But at the end of the eighteenth century a shift occurred, and some considered it "less essential to train docile subjects than to first make more subjects, to produce human beings who would become the state's most basic resource" (Badinter 1980:118). Children had changed in status; they had become a potential commercial value. "As the foresight of the late-eighteenth-century man grew, the child was transformed in his eyes from a short-term burden to a long-term productive force, a profitable investment for the state, one that it would be very stupid and 'improvident' to neglect" (Badinter 1980:130).

Therefore, the waste of human beings had to be avoided at all costs, and the new imperative was the survival of children. To affect this rescue, mothers were "summoned to return to their maternal duties" (Badinter 1980:151). The task demanded of them must have seemed quite onerous, reluctant as they were to set to work. It took several decades, and many pleas, sermons and indictments before women finally set their minds to "fulfilling their duties as mothers". For more than a century a three-pronged argument was constantly intoned: "Ladies, you must heed the voice of nature; if you do, you will be rewarded, but if you ignore it, nature will be avenged and you will be punished" (Badinter 1980:152).

Writers, administrators and doctors set to work and brought into play their most subtle arguments to convince women to take a personal interest in their children. As a result, maternal watchfulness became an

obsession. There was not a single day or night when the mother did not affectionately watch over her little one. The greatest of maternal crimes, which she feared most, was neglect (Badinter 1980:177).

#### **2.5.4 The twentieth century and the trap of motherhood**

Motherhood took on a new and different meaning in the twentieth century. Enriched by new duties, it extended beyond the inevitable nine months to include responsibility for children's proper upbringing and a major part of their intellectual development. There was a new awareness that the mother's function went "beyond the biological to the moral; it was her duty to raise a good Christian and a good citizen, a person who would benefit himself and society .... It was 'nature', they said, that assigned her these duties" (Badinter 1980:205). According to Foucault (1977:138), the discipline needed to produce subjected and practised bodies, the "docile bodies", sometimes circulated very rapidly from one point to another, and were adopted in response to particular needs. In this case, mothers were "turned into a relation of strict subjection" (Foucault 1977:138), in order to produce the kind of subject needed by society.

The doctor's helper in the eighteenth century, the priest's and teacher's in the nineteenth, the mother would "shoulder a final responsibility in the twentieth. She would be accountable for her child's unconscious mind and the fulfilment of his desires" (Badinter 1980:205).

#### **2.5.5 Mechanisms of power that recruited women into the trap of motherhood**

Ideas from the French philosopher, Michel Foucault, can explain how these dramatic changes in the behaviour of mothers were possible; how women were convinced that their "own needs and desires have no place .... [That] the ideal for feminine goodness was selfless care for others" (Weingarten 1994:65). According to Foucault (1980:119), power exists throughout all social relationships, and is therefore unavoidable. "It needs to be considered as a productive network which runs through the whole social body" (Foucault 1980:119). The force of power does not lie in the ideas people have about it, but it shows itself "in the day-to-day social practices, in the construction of subjectivities, and in the forms of knowledge that come to be possible" (Flaskas & Humphreys 1993:44). Power "produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production" (Foucault 1977:194).

Foucault looked at power in its positive or reproductive potential, as well as its negative potential. Positive and negative forms of power can be equally oppressive, in the sense that power may create subjectivities of, for example, the "good mother". This definition of personhood can be as oppressive as any formal social restrictions or controls (Flaskas & Humphreys 1993:43).

The panopticon is an important mechanism of control of the subject and subject control, for it "automizes and disindividualizes power" (Foucault 1977:202). The strength of power has its roots "not so much in a person as in a certain concerted distribution of bodies, surfaces, lights, gazes; in an arrangement whose internal mechanisms produce the relation in which individuals are caught up" (Foucault 1977:202). It serves to "promote an externalised cultural (normative) 'gaze' which is internalised by the subject, and moves the subject to practices of the body deemed desirable by the culture of power" (Madigan 1998:19). The mechanisms of the disciplinary establishments have a tendency to become "de-institutionalised": the "massive, compact disciplines are broken down into flexible methods of control" (Foucault 1977:210). For example, the "Christian school must not simply train docile children; it must also make it possible to supervise the parents" (Foucault 1977:211).

Self-formation takes place through a variety of operations on people's own bodies, thoughts and conduct. These operations entail "a process of self understanding through internalised dialogue mediated through external cultural norms" (Madigan 1998:19).

We are "judged, condemned, classified, determined in our undertakings, destined to a certain mode of living or dying, as a function of the true discourses which are the bearers of the specific effects of power" (Foucault 1980 :94).

White and Epston (1990:24) outlined Foucault's idea about the technology that became available to recruit persons into an active role in their own subjugation. People become the guardians of themselves, when

- conditions are established for persons to experience ongoing evaluation according to particular institutionalised "norms"
- these conditions cannot be escaped
- persons can be isolated in their experience of such conditions

In these circumstances, persons will perpetually evaluate their own behaviour and engage in operations on themselves to force themselves into "docile bodies" (White & Epston 1990:24). According to Foucault, we live in a society where evaluation or "normalizing judgement" (Foucault 1977:177) has replaced the judiciary and torture as a primary mechanism of social control.

This notion of normalising discourse (Foucault 1980:116) also applies to motherhood. As ideals of good motherhood became fixed into policies, for example in relation to feeding of infants, it became feasible to

apply these standards through teams of health visitors, doctors or social workers. Silva (1996:48) points out how these standards differed over time. In 1978 the mother who fed her child on demand from a tube, and the mother, who started too soon to feed her infant solids, became inadequate mothers. Good mothers either breast-fed her infant herself, or fed from a special and hygienically prepared bottle every four hours. Later on, only breast-feeding defined the good mother, and it was deemed that she fed on demand and never to schedule. We can think of numerous examples of minute practices that the good mother was prescribed to follow, of which the bad mother remained, or so it was assumed, deliberately or wilfully ignorant. These rules can be seen in Foucauldian terms as the "calibrations of good motherhood" (Silva 1996:46). Initially these prescriptions covered mainly physical matters of diet, warmth, immediate environment and physical development of the infant. Later these calibrations were extended to include the immense realm of the psychological care and nurture of the child. Therefore, "the good mother was no longer the one who fed and cleansed properly, she would be inadequate if she failed to love *properly* and to express this love in the *correct* fashion. Love, for example, should not be expressed by spoiling the child, but by very precise gestures and attitudes that were geared towards making the child an acceptable citizen" (Silva 1996: 46).

The fact that the content of the calibrated rules of motherhood changes reveals that there is nothing "natural" in these manifestations of supposedly instinctive behaviour. The fact that the content changes does not weaken the overall strength of the system of rules. The significance for Foucault of normalising discourses (Foucault 1980:116) is the way in which degrees of adherence to the rules are secured by the stigmas and impositions placed upon those who disregard them. "Thus we can think in terms of 'tests' that were and are imposed routinely to discover whether mothers met or fail the standards of motherhood" (Silva 1996:47).

Just as these techniques were developed at a local level, it is at this level that the effects of power are the least concealed and therefore most available to critique. The effects of power can only be challenged from within the power relationship itself, and it is the idea of the "always-present potential for resistance that offers some optimism for change in oppressive power relationships" (Flaskas & Humphreys 1993:44).

### **2.5.6 The cult of motherhood and the birth of mother blaming**

Mothers behave in a way that is dictated by the culture of the society they live in. During the post-industrial revolution, children became the hope of the economy and their training as productive citizens a critical task. "The 'discovery' of the child led to the 'cult of motherhood'. Images of mothers became polarised; mothers were either saintly, all nurturing, and self-sacrificing, or cruel and ruthless" (Weingarten 1994:29).

Weingarten (1994:41) refers to the myth of maternal omnipotence: "Good mothers were powerful enough to create healthy children, and bad mothers were powerful enough to create dysfunctional ones" (Weingarten 1994:41). According to Weingarten (1994:41), these ideas shaped prevailing thoughts about mothering: that "mothers are responsible for the fate of their children". When the dominant ideology takes maternal responsibility as a fact, women are "idealized when their children succeed and blamed when they do not" (Weingarten 1994:42). Heffner (1980:21) refers to motherhood as "a high risk profession". She also refers to the belief that if something goes wrong, someone is at fault and "too often that someone is mother".

This formulation was legitimised by the impact of Freudian theory on child-rearing practice. The goal of child rearing shifted from the socialisation of the child to the mental health of the child, from "teaching the child to live in society to a concern with self-realization" (Heffner 1980:21).

Due to the influence of psychoanalysis, the mother's role would be elevated to include principal responsibility for her offspring's happiness – a terrifying assignment completing the definition of her role, her mission in life. Although the successive burdens loaded upon her went hand in hand with the enhanced image of the mother, it "concealed a twofold trap, sometimes experienced as the surrendering of her freedom" (Badinter 1980:206).

- Trapped in the role of mother, women would no longer be able to escape it without inviting moral condemnation. Working women, childless women or women who did not want to have children, found themselves marginalised and excluded.
- Those women who could not, or did not know how to perform the tasks of motherhood perfectly, were condemned. "From responsibility to guilt there is only one step, quickly passed over when the child has the slightest problem. Henceforth it would be the mother who would be called to account for any and all deviations from the ideal" (Badinter 1980:206).

While some women blossomed in the role of mother and joyfully accepted this heavy burden, others could not without anxiety and guilt, adjust to the strictures of the new role that had been foisted upon them.

"Feminine nature" had been defined as synonymous with all the characteristics of the model mother. Both Rousseau and Freud .... emphasized the sense of devotion and sacrifice that characterized, in their view, the 'normal' woman. Trapped in this definition by such authoritative sources, how could women escape from what was agreed to be their nature? Either they could stick to the prescribed model as closely as possible, or they could try to stand apart from it, in which case there was hell to pay. Accused of selfishness, of spitefulness, of being unbalanced, the women who challenged the dominant ideology could only try to accept, to one degree or another, her 'abnormality'. And abnormality, like any difference from the norm, is hard to live with. So women submitted silently, some pacified and calmed, others frustrated and unhappy.

Badinter 1980:206-207



Psychoanalysts have acquired fame and fortune by sketching the portrait of the good mother and by giving advice to women through the mass media or in books written especially for them. "The success of these first popularisations of psychoanalytic theory was and is sufficient proof of the confusion felt by mothers and their belief in an ideal – contradictions of the idea that maternal behavior is instinctive. The mother's every move was subject to corrective prescriptions" (Badinter 1980:274).

Advisers (like Drs Spock, Dolto and Winnicott) presented their advice in books, women's magazines, radio and television programmes. Maternal responsibilities reached their high point, resulting in a diffuse sense of guilt for the mother has been set up to feel responsible and therefore guilty at the child's slightest psychological difficulty.

According to Heffner (1980:24), guilt is the inevitable outcome of the three major messages that have been communicated to mothers about child rearing:

- A good mother will think first and foremost about the needs of her child. Child-rearing information for mothers is focused on educating mothers about a child's needs
- Great harm can come to a child if her/his needs are not met properly, and mothers have great potential for damaging their children
- There is a right way and a wrong way of responding to a child, and if the mother makes a mistake and does it the wrong way, she will irreparably ruin her child.

These messages have all been communicated in a body of literature that both mystifies and oversimplifies child rearing. According to Heffner (1980:25), there is usually a great discrepancy between the expectation offered to the mother and the mother's achievement. Her child's behaviour often does not follow the storybook version. Her own feelings do not match the way she has been told she ought to feel. All of this leaves her feeling worried, incompetent and inadequate. She thinks there is something wrong with her or her child. Either way, mothers tend to internalise this blame themselves, even in circumstances when they are powerless to shape their children's destiny.

### **2.5.7 Finding the mother's voice**

The stories we make of our lives are constructed within certain constraints, and it is exceedingly difficult to tell tales that diverge from the dominant stories of our culture. Cultures select some versions of stories to legitimate and others to deny, repress, trivialise, marginalise and obscure. This happens in cultures at large, like Western civilisation, as well as in small cultures like medical wards and families. Some mothers

are so sensitive to the ways their feelings and experiences may not be acceptable to the culture that their voices are silenced. "A mother may silence or distort her voice in reaction to the contradictions she finds between what she believes (and others say) her experience should be, and what it simply is" (Weingarten 1994:3). Can that be the reason why, as Weingarten (1994:34) points out "though we have countless works written by women ... the voice of the mother is still hard to find"?

What I want for mothers is to be free of anxiety and guilt, to be able to make informed choices regarding their mothering practices – or even the choice not to have children. I can only agree with Romito's (1997:186) wish for the future:

I should like to contribute to a society that gives worth and legitimacy to the choice of not having children, on the one hand and is able to assure all mothers decent conditions in which to raise their children enjoyably, on the other, I should like to live in a country where not everyone has to have a child, but where everyone feels deeply responsible and ready to care for the children already with us.

If mothers are to be successful in achieving their child-rearing goals, they must have "the inner freedom to find their own value system and within that system to find what is acceptable to them and what is not. This means leaving behind anxiety, but also the security, of simplistic good-bad formulations and deciding for themselves what they want to teach their children" (Heffner 1980:55).

"If we believe that children have the right to be heard as well as seen, we must begin by hearing their mothers. Only as they themselves are more fully understood will they be able to apply this same understanding to their children" (Heffner 1980:116).

Although the pressures of what it takes to be a "good mother" apply to all mothers, they are "particularly isolating when the challenges of being a 'good mother' are heightened by disability" (Greenspan 1998:44). In the following section I will discuss some ideas on ableism and its isolating effects on differently abled people and their families.

## **2.6 ABLEISM**

Graham (1996:21) refers to Lyotard and states that "the grand narrative of progress, optimism and rationalization which once claimed the hearts and minds of western civilization cannot encompass the diversity and specificity of local interests. In fact, metanarrative is an abuse of difference, absorbing and smothering variety and pluralism into a global universal homogeneity". The result is what is being referred to as "ableism" (Davis 1999:1; Ellis & Llewelyn 1997:113; Keane 1998:121; Reinhartz 1992:258; Weeber 1999:1).

"Ableism", a term dating from the late twentieth century, refers both to the belief that persons with disabilities are inferior to persons without disabilities and to practices of discrimination and violence against persons with disabilities (Ellis & Llewelyn 1997:113). Feminists and feminist theologians also refer to ableism, as "the lack of consideration and justice towards those with physical or mental disabilities" (Keane 1998:121). According to Davis (1999:1), it is an "'us-them' division which also neatly enforces the hegemonic demands that one be 'normal'" (Davis 1999:1). For Weeber (1999:1), a woman with disability, ableism is the "unconscious beliefs of a society that assumes everyone is, or should be, 'normal'".

Davis (1999:2) distinguishes between impairment and disability. Impairment is seen as a physical deficit or difficulty. But impairment "becomes a disability in a society that makes that difference into a lack". Eiesland (1994:48) distinguishes between the "physical contingency that is part of ordinary life and socially constructed barriers that make ordinary life impossible".

### **2.6.1 The genealogy of ableism**

According to Foucault (Fillingham 1993:16), societies, knowledge/power and the human sciences have, since the eighteenth century, carefully defined the difference between normal and abnormal, and then used these definitions to regulate behaviour. Although it appears to be easy to differentiate between the normal and abnormal, it is in fact extremely difficult as there is always a hazy and highly contested borderline.

In earlier times no one expected disabled or disfigured people to stay out of sight, but our society has increasingly locked up, excluded and hidden "abnormal" people while watching, examining and questioning them carefully. This exclusion of abnormal people does not make them unimportant to the culture, for "only through abnormality do we know what normal is" (Fillingham 1993:17).

This study of abnormality is one of the main ways in which power relations are established in society. "When an abnormality and its corresponding norm are defined, somehow it is always the normal person

who has power over the abnormal" (Fillingham 1993:18). Although psychologists and physicians talk about their patients, the latter are not expected to talk about the former – "what they have to say has already been ruled irrelevant, because by definition they have no knowledge (but that is code for not wanting them to have any power)" (Fillingham 1993:18).

The ideas of disciplinary power introduced by Foucault can also offer an explanation to the origin of ableism. According to Foucault (1977:182), the regime of disciplinary power brings five operations into play:

- It refers individual actions to a whole that is at once a field of comparison, a space differentiation and the principle of a rule to be followed.
- It differentiates individuals from one another, according to an average towards which one must move.
- It measures in quantitative terms and hierarchises in terms of value the abilities, the level, the "nature" of individuals.
- It introduces, through this value-giving measure, the constraint of a conformity that must be achieved.
- It traces the limit that will define difference in relation to all other differences, the external frontier of the abnormal.

The perpetual penalty that "traverses all points and supervises every instant in the disciplinary institutions compares, differentiates, hierarchizes, homogenizes, excludes. In short, it *normalizes*" (Foucault 1977:183). This normalisation becomes one of the great instruments of power at the end of the classical age. The marks that indicated status, privilege and affiliation were increasingly replaced by a whole range of degrees of normality, indicating membership of a homogeneous social body. Therefore, the "power of normalisation imposes homogeneity" (Foucault 1977:184). It is this "normalising gaze, a surveillance that makes it possible to qualify, to classify and to punish" (Foucault 1977:184).

The normal/abnormal dichotomy displaced an earlier paradigm based on a notion of the ideal, which was linked ideologically to structures of kinship and feudal society, where an ideal (ruler, form, palace, god) occupied the pinnacle of a social-cultural triangle, and all other instantiations were by definition below the ideal. The change from feudalism and mercantilism to capitalism required new forms of subjectivity and symbolic production, and that most perfect of subjects – the average citizen – had to be created (Davis 1999:2).

Symbolic production on the ideological level should aim at the "creation of average, that is non-heroic, middleclass, 'real' citizens. In this sense, real means average" (Davis 1999:2). Society spent over the

centuries much of its culturally productive time trying to find exactly what average meant, and the concept of "normal" was born.

The normal citizen was a necessary development for capitalism. It was this "[a]ble-bodied citizen worker who would be endowed with qualities necessary for factory work .... To form this good worker, the antithesis had to be created in the cultural and ideological imagination – the deformed, disabled, non-national, non-compliant bad worker" (Davis 1999:3).

When we study the history of disability, we are really studying the history of "how capitalism normalized the body and made it compliant to an expedient economic agenda" (Davis 1999:3). Disability becomes defined as a characteristic that invalidates the ability of workers to work, causing public policy to define "the disabled" as belonging to the deserving poor. "The binary continues, then, between able-bodied worker-citizens and disabled, non-worker dependants" (Davis 1999:3).

Standards of normalcy affect "the very way that we think about what it means to be a person, and the way that we feel about a person's inherent worth" (Greenspan 1998:47). We therefore think of certain lives as more worth living than others do. According to Greenspan (1998:47), Hitler brought this way of thinking to its fascist extreme, by cleansing society from "useless eaters" - and first on his list were mental and physical "defectives".

Within the Christian tradition there is a persistent thread that disability denotes an unusual relationship with God. The person with disabilities is "either divinely blessed or damned: the defiled evildoer or the spiritual superhero" (Eiesland 1994:70). This biblical record has shaped our life together as Christians and formed widespread cultural attitudes regarding disability. For example in the Old Testament, in Leviticus 21:18-20, anyone "blind or lame, or one who has a mutilated face or a limb too long, or one who has a broken foot or a broken hand, or a hunchback, or a dwarf, or a man with a blemish in his eye" is prohibited from the priestly activities of bringing offerings to God or entering the most holy place in the temple.

The New Testament also supports the theme of a link between sin and disability. In the account of the man with paralysis who was lowered by companions into the house where Jesus was speaking (Luke 5:18-26), forgiveness of sin and physical healing are presented as equivalent. In John 5:14 Jesus also said, "Do not sin anymore, so that nothing worse happens to you" after he had healed the man, who had been unable to walk at the pool of Bethesda (Eiesland 1994:71).

Theological interpretations of the meaning of perfection have historically included physical flawlessness, as well as absolute freedom. According to such standards, people with disabilities "lack perfection and embody un-wholeness" (Eiesland 1994:72).

The biblical theme of charitable giving has also shaped patterns of interaction between able-bodied individuals and those with disabilities. Historically, church-based charitable societies have also merged charity and healing, establishing numerous hospitals and clinics for people with disabilities. Although the benefits of these organisations should not be underemphasised, one unintended outcome of some charitable societies has been the environmental and social segregation of people with disabilities, as well as the segregation from the Christian community rather than restoration to social and religious participation (Eiesland 1994:74).

## **2.6.2 The face of ableism**

Disabled persons describe the pain of "living in waters far beyond the main stream" (Perry & Gentle 1997:25), for example:

"[A]bleism causes pain because it convinces us that there is something fundamentally wrong with us, that we are not acceptable just as we are. After all, we are the ones who are 'defective', with bodies ... to be fixed by doctors and therapists" (Weeber 1999:1). It also causes pain to non-disabled people who are unprepared to deal with their own vulnerability and mortality when accidents and ageing require that they do so" (Weeber 1999:1). Hastings (1997:9) invented the term "nyd", referring to a "not yet disabled" person.

Ellis and Llewellyn (1997:113) define three categories of ableism: individual, cultural and institutional ableism:

### **1. Individual ableism**

Individual ableism refers to the prejudices held by a particular person. Both persons with and without disabilities believe and act on traditional constructs of disability (disability as a curse, as sin or evil, as something to be pitied, as something to be corrected or cured). Some acts of individual ableism are deliberate and some are unconscious.

## 2. Cultural ableism

Cultural ableism refers to the prejudices held by members of a particular culture or community, or deeply held social attitudes about disability. It can be found in sources "as diverse as the Bible, Shakespeare and Batman movies" (Ellis & Llewelyn 1997:114).

The effect of these cultural ideas is that disabled people spend enormous amounts of time and energy trying to prove how able they are – to counter society's belief that they are "unable". Weeber thought she had passed as normal because she was often complimented by strangers and friends who did not think of her as "handicapped", until she realised how her life had been lived as an outsider, struggling unconsciously for acceptance (Weeber 1999:2).

Thorne (1997:30) refers to the "achievement treadmill" or scales of achievement by which the lives of disabled people are judged and assessed by society. She refers to all sorts of evaluations like "how independent she will be" or "how worthwhile or productive will she be". Since not everyone is going to reach this "pinnacle of success", such a linear-based notion is restricted and exclusive, which excludes the experiences of many people. It is, however, a very dominant notion in Western society. Therefore, some people "keep striving to match up to these cultural expectations and get knocked down in the process. Just because everyone thinks that it's the best thing to be doing we have to strive for the next goal" (Thorne 1997:30). Weeber (1999:1) resonates with this idea when she describes ableism as "the assumption that everybody should be capable of total independence and 'pulling themselves up by their bootstraps'". Greenspan (1998:51) also refers to the "myth of independent individualism", which is according to her, a "denial of our fundamental interdependence as human beings". We cannot stand looking at people who are visibly different and "needy", because they remind us that "we too, are vulnerable; that we are dependant on others; that we have needs, which we consider ... to be shameful weaknesses without merit" (Greenspan 1998:51).

Due to these cultural ideas the focus of many families is to adapt their child to a society that needs them to be "normal". This sometimes leads to extreme and painful measures that are taken to "fix" them, measures that go beyond what may be truly needed to ensure their full, unique development (Weeber 1999:4).

In the face of cultural ableism, the social marginalisation of mothers of differently abled children is "at the heart of what's overwhelming about raising a 'different' child" (Greenspan 1998:43). In a society in which the intolerance of difference is endemic to our way of thinking, mothers are forced to keep silent about the

physical and emotional demands of the daily routines of caring for their disabled children, believing that "she must bear her lot stoically to be a 'good mother'" (Greenspan 1998:44).

### 3. Institutional ableism

Institutional ableism is a system of economic and social discrimination against persons with disabilities. It is an inherent bias against persons with disability built into the structures of society. An example of institutional ableism, is when a person with a wheelchair is unable to work because her city does not have wheel-chair accessible buses. Accessibility means "the availability of the same choices accorded to able-bodied people" (Eiesland 1994:28).

#### 2.6.3 Deconstructing the belief systems that support the notion of ableism

As long as the problem of the disabled is located in the body of the person with disabilities, it will never be conceptualised as political and resolved politically. As long as the person with disabilities is seen as an anomalous occurrence rather than part of a continuum, we will continue to foster the ideology that all people are created normal and should remain so. As long as normality is allowed to remain an invisible but regnant concept, it will continue to keep people so busy "trying to conform to a standard that they ignore the injustice it causes" (Davis 1999:3).

For McLean (1997:3) the deconstruction of ableism starts by creating new possibilities for living a life in different ways by untangling yourself from social expectations and definitions of what make a "normal life". Disabled people should stop attempts to struggle against the demands of the disabled body to try to conform to "mainstream ways of living" (McLean 1997:3). For Weeber (1999:3) it was an act of liberation – and resistance - when she stopped spending most of her energy walking to get around, and begun to use a scooter for mobility. She is "proud to have found my way home to the disability community .... I now also know the liberating power of embracing my disability and of celebrating who I am because of it" (Weeber 1999:4). She no longer viewed her disability as a problem to be solved, but as "a disability to be lived with" (McLean 1997:3).

The specific stories of people with disabilities are prerequisites for the deconstruction of ableism. Yet Eiesland (1994:31) warns against the misuse of these stories, when she says,

"Our distinct narratives have too frequently been simplistically recast into standard tales of 'overcomers', a genre of disability literature that elevates the individual who conquers disability and achieves success. These stories often leave the impression that with great personal effort people with disabilities can overcome our physical limitations and the social barriers. They emphasise



personal qualities as determinative of success and ignore discrimination and disabling social policies".

Eiesland (1994:32) refers to a person with a congenital disability that has never internalised able-bodiedness as the norm to which to aspire. She was able to see her own body as different, but not defective. She does not "pass" or compensate socially for her disability; she rather "claims her body as authentic space".

Greenspan (1998:47) refuses to carry the condition of shame for being "not normal". For her, refusing to do so makes every day an opportunity for resistance.

However hard we try, we cannot deny the fact that "tension is a prime characteristic of families with differently abled children" (Ikeler 1990:234). Some of these stresses can be reduced through, among others, pastoral and congregational care. In chapter five, I discuss some ideas on practical theology and pastoral care for families with differently abled children.

In the next chapter I briefly outline the research journey, and I introduce the participants who took part in the research journey, sharing their stories of raising their differently abled children.

## **CHAPTER 3: THE RESEARCH JOURNEY – A HUMAN STORY**

### **3.1 INTRODUCTION**

In this chapter I focus on an outline and a brief overview of the steps or destinations on the research journey (Reinharz 1992:211), where the stories of the "research participants merge[d] with that of the researcher in order to create new stories" (Bishop 1996:26). See paragraph 3.1.8, where Ackermann (1996:48) also refers to the change of stories at the intersection with other stories. I will discuss the use of pastoral narrative practices in a group setting as a community of care (Dixon 1999:232). The effects of "taken for granted truths" (Morgan 2000:45) regarding motherhood and ableism on the mothers of differently abled children will also be noted/explored. Lastly, I will introduce the participants who took part in the journey.

### **3.2 DESTINATIONS ON THE RESEARCH JOURNEY**

The following section provides an outline and discussion of the steps or destinations on the research journey (Reinharz 1992:211).

#### **3.2.1 Destination one – finding participants**

I advertised for voluntary participation by mothers with differently abled children at a school for differently abled children, as well as a Dutch Reformed Congregation (see appendix A). I invited all the mothers who contacted me in reaction to the invitation to an information session.

Six mothers attended the session. Each participant introduced herself to the group. I gave a brief overview of the research project, and presented the information sheet (see appendix B). After the mothers had time to familiarise themselves with the content of the information sheet, I explained the terms of the study, as well as the ethical implications. We discussed the questions that they raised. One of the main concerns of the women was the consent form the children were expected to sign. Except for one, all the participants preferred not to involve their children in the project. They thought the children were suffering enough, without the added stress of wondering what their mothers had to say about them. The mothers were also concerned that their participation in a project like this could convey the impression that parenting "is too much" for them and that the idea could also add to the stress the children already had to cope with. Consensus was reached that if the children's identities were concealed, the mothers felt comfortable to talk about their children without any harm done to the children, and preferred the children not to give consent. However, I had already asked my son Henk for consent before I entered into this project. I also use his

name in this project with his permission. (See appendix C for his signed consent form.) I experienced the conversation to open up an opportunity for us to talk about ableism and its effects on our lives.

All the women who attended the session signed the consent forms (see appendix D). The group decided to continue with the first session.

### **3.2.2 Destination two – negotiating the journey**

I informed the participating mothers about my inspiration and my preliminary aims for the project, as well as my ideas about how to journey together, and requested their inputs and preferences. I considered this discussion necessary to come to a mutual agreement on the title of the project and terminology to be used, the aims for the project and the way in which we mapped the journey. In order to ensure that the participants were co-creators and primary beneficiaries of the project, I assumed that the actual project could be totally different to the project I had initially intended. Following an approach of power sharing and self-determination (Bishop 1996:21), we agreed that the goals and aims of the study would be continuously negotiated with all the participants. I explained that since an end result could not be fixed from the start, my ideas of our shared journey only served as a guideline by which the study could develop. We therefore agreed to pause the process from time to time to reflect on our journey, and to amend it if necessary.

The group planned the time and venue for the following sessions. Eight group sessions were scheduled, over a period of four months, starting on 9 June 2001, with the final session on 13 October 2001. The sessions were scheduled fortnightly (except during the school holidays) on Saturday mornings to allow me time to compose the summarising letter to the group, as well as for my supervisor to read the letters and make recommendations. There was no time limit to the length of the sessions. The average duration of each session was two and a half to three hours.

We concluded that should one participant not be able to attend, the session would continue as planned, and the absentee would receive the summary of the session. At first we decided that should more than one participant not be able to attend, we would reschedule the session. In the end we decided to proceed with the planned sessions even though more participants were unable to attend. The group decided to continue with the meetings at my house, as this was the central place, and the participants were satisfied that their privacy was protected. I provided tea and some snacks.

The group decided on the following guidelines for us to follow on our research journey:

- I wanted to write the research report in English because of a wider reading public. However, most of the participants were Afrikaans-speaking. Those who were English-speaking, were married to Afrikaans-speaking men, and completely comfortable to speak Afrikaans. They were satisfied that the group discussions were in Afrikaans, while the Afrikaans-speaking women were satisfied that everything in writing would be in English.
- The sessions were tape-recorded, transcribed and summarised.
- The participants received a summary/letter after each session, before the next session. Everyone could comment, correct, or provide feedback regarding the summary/letter. The summaries/letters were e-mailed to the participants who had access to electronic mail, to an address where they were confident that their privacy was protected. Other arrangements were made for one participant who did not have access to electronic mail.
- Each of the participants chose a name to be used in the report, for both her and her child.

A seventh participant joined the group at the second session.

An extra session (the seventh one) was scheduled to accommodate the pastor of one of the participants. He wanted to attend a group session in order to compose the sermon he undertook to dedicate to the cause of consciousness raising for differently abled people (see paragraph 5.6).

The group decided to conclude our research journey with a ritual. Originally the idea was to bury the expectations we had for our children that did not materialise, and to light a candle as symbol of the hope we have for the future of our children. However, each participant decided on a ritual, and symbolic actions that suited her unique circumstances (see paragraph 4.14).

### **3.2.3 Destination three – hearing their stories**

From a qualitative research perspective, as proposed by feminist researchers, I followed an approach of narrative/free-ranging conversations where the interviewees helped set the research agenda (Bishop 1996). The group conversations focused on the stories of mothers with differently abled children, struggling in silence with their everyday obstacles, trying to do the best they can for their children. Although I had an agenda with certain ideas that I wanted us to discuss during the sessions, the group discussions developed a "life of its own". As it was the first time for the participants to join a group process discussing their experiences of mothering differently abled children, it was almost as a dam wall gave way. The participants flooded the sessions with words and ideas that were contained for so long. I decided to discard any

agenda, and allow the participants to determine the topics for discussion, and to talk about the things that were important to them. Most of the time, experiences of the participants during the week preceding the session introduced the topics for the session.

During the group discussions I engaged in, among others, pastoral narrative practices. Like Dixon (1999:232), I found many crossovers between pastoral narrative practices and the methodological stance (see paragraph 1.5) of this research. Although the project was not about doing therapy with the participants, it turned out to be research as therapy, as ethically I was attuned to the participants that they should firstly benefit (Dixon 1999:233). In this sense, what applies to therapy, also applies to this participatory research project. In the following paragraphs I discuss some of the practices that guided the group discussions.

*The client is the expert:*

Human systems are seen as existing only in the domain of meaning or intersubjective linguistic reality. In the domain of meaning, social systems are communication networks that are distinguished in and by language. Meaning within a particular social context is evolved through the dynamic social process of dialogue and conversation. Problems can be thought of as "lumps of meaning" in a batter whose consistency is always changing through dialogue" (Anderson & Goolishian 1988:387).

Therapy (or, in this case, participatory research) is thus a "linguistic event that takes place in ... a therapeutic conversation. The therapeutic conversation is a mutual search and exploration through dialogue, a two-way exchange, a crisscrossing of ideas in which new meanings are continually evolving toward the 'dis-solving' of problems .... Change is the evolution of new meaning through dialogue" (Anderson & Goolishian 1988:372). Anderson and Goolishian (1988:381) believe that therapy, and in this case the group discussions, is "a process of expanding and saying the 'unsaid' - the development, through dialogue, of new themes and narratives and, actually, the creation of new histories. Therapy relies on the infinite resources of the 'not-yet-said' in the narratives around which we organize ourselves in our conduct with each other .... The realization of change requires communicative action, dialogue, and discourse".

The role of the therapist, and in this case the researcher with "insider knowledges" (White 1997:206), is that of a "master conversational artist – an architect of dialogue – whose expertise is in creating a space for and facilitating of a dialogical conversation. The therapist is a participant observer and a participant manager of the therapeutic conversation" (Anderson & Goolishian 1988:372).

Conversational or therapeutic questions are the primary instrument to facilitate the development of conversational space and the dialogical process. To accomplish this, the therapist exercises "an expertise in asking questions from a position of not-knowing" (Anderson & Goolishian 1992:29). Not knowing requires that our understandings, explanations and interpretations in therapy be not limited by prior experiences or theoretically formed truths and knowledge. It also entails a general attitude or stance in which the therapist's actions communicate "an abundant, genuine curiosity" (Anderson & Goolishian 1992:29). New futures result from developing narratives that give new meanings and understandings to one's life and enable different agency. In therapy, this is best accomplished by "questions born of a genuine curiosity for that which is 'not-known' about that which has just been said" (Anderson & Goolishian 1992:29). A therapist using this stance moves away from the expert role, and people in therapy are viewed as the experts of their own lives. "This implies not asking questions from a position of pre-understanding and not asking questions to which we want particular answers" (Freedman & Combs 1996:44). This approach does not mean that the therapist's experiences and knowledge are not used, it just means that they are to be considered no more valid than those of the client are. "The client has local experiences, while the therapist has general experiences" (Andersen 1993:321).

As Anderson (1997:247) puts it: "[A]ll participants are learners and are subject to change as they share and explore each others voice; as voices connect and intertwine constructing something new and different for each."

Understanding is always interpretative, and language and history are always both conditions for and limits to understanding. Therefore, the outcome of an interview could not be predicted beforehand. Each participant's story was dealt with individually and the course of the research developed according to the outcomes of the different stories that were told.

#### *Participatory mode of consciousness:*

I conducted the group discussions in a participatory mode of consciousness. According to Heshusius (1994:16), participatory consciousness is the awareness of a deeper level of kinship between the knower and the known. It requires an attitude of profound openness and receptivity. It involves identification or merging that "bespeaks a psychic wholeness".

To be consistent with postmodernist premises, academic thinking, researching and writing should move freely between the personal, the theoretical, and the political/institutional dimensions of experiences. Through focus on ... 'biography, history, and social structure', we can explore ... relationships between individuals' ... life-histories, our historical and material contexts, and the

broader patterns of power-relations which shape and constrain our possibilities ... through which we create our ... theories.

(Middleton 1995:91)

### **3.2.4 Destination four – re-authoring conversations in a community of concern**

One of the objectives of a pastoral narrative practice is to render transparent the discourses and the effect these have on individuals' lives and relationships: "[A] person's identity is viewed within the politics and power plays of a culturally manufactured and constituted self .... Community discourses can thus be seen as the rules we formulate by which we decide what is normal and what is not" (Madigan 1996:50). Morgan (2000:45) prefers the term "taken for granted truths", while Gerkin (1991:54) refers to the "shaping of common sense by cultural traditions". The term "common sense" refers to "commonly held understanding of the way life is or should be .... Common sense is seen primarily in the judgements about right and wrong, proper and improper" (Gerkin 1991:54). These common sense norms can become so internalised that people exclude others with different ideas without realising it. Gerkin (1991:73) uses the example of the congregation saying "everyone welcome" when they actually mean "everyone like us welcome". The issue that Gerkin refers to in this example is racism, but it could also be applied to any marginalised group, like differently abled people.

Following the ideas of social construction theory and a pastoral narrative practice, the stories of the mothers were deconstructed (a) to uncover and interrogate the discourses or "taken for granted truths" at work and (b) to re-author (White 1997:230) alternative preferred stories with the participants in the re-telling of these.

Dixon (1999:232) adds to the notion "community of care", Epston's idea of "communities of concern" and suggests that we unpack the research metaphor and approach issues in such a way that all participants will benefit from the conversations and will be able to make significant contributions towards the process. These contributions include both the participants' knowledges, as well as the knowledge that will be co-constructed by researcher and participants. As Adams-Westcott and Isenbart (1995:335) put it, "[w]e invite group members to develop connections and create a community that supports each participant's personal journey of change. This 'community' provides an audience for members to (1) develop their own self-knowledge, (2) practise more validating stories about self, and (3) incorporate preferred narratives into their lived experience".

From the perspective of pastoral care, "most people's preoccupations have more to do with everyday life and its dilemmas" (Gerkin 1991:12). Gerkin (1991:14) also emphasises the importance of a caring

community when he argues: "in the society of pluralism and individualism [many] are searching ... to rediscover a sense of community and consensus". According to Gerkin (1991:118), the primary role of the parish pastor, and for the purpose of this study I would like to add the pastoral therapist or researcher, is "the nurturing and strengthening of the ties that bind a religious community to ... a sustained and sustaining relational network". He refers to persons in search of a religious community, moving toward becoming "at home" with fellow Christians – "at home both in the sense of having found a place where their religious needs and desires may be focused, and in the sense of having found a network of human relationships in which they feel secure and valued" (Gerkin 1991:118).

### **3.2.5 Destination five – reflective summary of group sessions**

Following each group session, I used the tape-recording of the session to summarise and to reflect on the session. After each session, I composed a letter to the group, summarising the session. It also served to extend the conversations (Epston 1994:31). The letters were helpful for externalising the concerns the participants brought to the conversations (Epston 1994:32). "Externalisation is the foundation from which many, though by no means all, narrative conversations are built" (Morgan 2000:17). In pastoral narrative practices, one of the first things the therapist, or in this case researcher, does is to separate the person's identity from the problem. Therefore the therapist begins speaking about the problem in ways that situate it separately from the person and his/her identity, based on the premise that the problem is the problem, as opposed to the person being seen as the problem.

Writing letters after the group discussions also provided the opportunity of "tuning in to what opens up new possibilities, any glimpse of an alternative to the ... problem saturated story" (Epston 1994:32).

The summaries were available to all participants to review and to edit according to their understanding. This added to my accountability towards the participants for they were given the opportunity to review my understanding of what we had said. The letters also helped me to reflect on my personal biased ideas and perceptions. If I were biased in one or another direction, they could correct my interpretation. I believe that this practice added to the truthfulness of the research.

The letters also served to invite the participants to enter into and become a part of the journey, adding to my commitment to participatory research.



### **3.2.6 Destination six – use of personal journals**

Dixon (1999:60) considers a journal “a place where selves can be constructed, reauthored, reflected upon, created, within a linguistic space”. She quotes Blodgett: “[I]f the ongoing writing reinforces a sense of one’s importance as an entity, reading it back helps piece out the design in that entity and redeclare its value. The dual process of writing and rereading may allow the writer to discover what her sense of essential identity is” (Dixon 1999:60).

The use of journals is in keeping with the notion of women “gaining a voice” (Belenky, Clinchy, Goldberger & Tarule 1986:16). Weingarten (1997b:xii) comments on writing as “a re-telling, a shaping of events that one has lived .... [T]he writer is no longer precisely the same person she is writing about”. The use of the personal journals was negotiated with the participants. They agreed to journalise their journeys with their differently abled children. They were given the choice to share snippets of the writing with other participants during the group discussions, or to remain in an inner dialogue with their journals. They chose to hand their journals to me. With their consent, I incorporated snippets of some of the journals in paragraph 5.3.1.

### **3.2.7 Destination seven – reporting the research**

By means of ongoing consultation with each participant to confirm my interpretation of what she had said, the story was co-constructed in the research report. I did not want to speak *for* the participants, but speak *out* for them. As the emphasis was on leaving the ownership of the research with the participants, each participant had the opportunity to review a draft of the report and comment on its validity. After the participants were satisfied that the report reflected their stories, each participant signed a consent form for release of information (see appendix E).

### **3.2.8 Destination eight – reflection on my personal story**

I had to realise that the group discussions were like a “mirrored room that can reflect back only the discourses brought to it” by the participants and myself (Hare-Mustin 1994:19). The predetermined content I brought to the conversations, was my “insiderness” (Reinharz 1992:260) or “insider knowledges” (White 1997:206) - my own experience of being the mother of a differently abled child and my personal baggage of discourses.

However, I also attempted to step outside myself and my practices and questioned it by following the advice of Hare-Mustin (1994:33):

- Develop self-reflectivity by trying to provide a special vision that can challenge the assumptions of my own discourses rather than merely going along with them.

- Acknowledge my own influence, my "author-ity", rather than deny it, by questioning my own views and why those are the questions I am asking.

It was my sincere intention to be informed/changed by the story of each participant and to create space for each participant to re-author her own story. "[A]ll realities are constructions, and some are more influential than others. By opening up the possibility of alternatives, a postmodern view moves beyond existing practices to their transformation" (Hare-Mustin 1994:33). "But we do not only hear others' stories. We have our own stories to tell. As these stories intersect, they change" (Ackermann 1996:48).

### **3.3 INTRODUCING THE GROUP PARTICIPANTS**

The seven participants in the group varied greatly regarding their and their children's ages, as well as the different abilities of the children. Some of the mothers suggested pseudonyms for themselves, as well as for their children. In the next paragraphs I introduce each participant.

The language the participants used to tell their stories, illustrated how their identities and the perceptions they had formed about themselves and their children were shaped by taken for granted truths.

Debbie is the mother of Walter, 19 years old. Walter is "a right-sided hemiplegic, and he also suffers from epileptic seizures". To Debbie, it "seems as if things get worse the older he gets". He attends the New Hope School. Debbie is concerned about "his lack of motivation. Sometimes I think he is lazy". She also describes him as "always swimming against the stream".

Suelene is the mother of a three-year-old son, Anton, born with spina bifida and hydrocephalus. Although the doctors did not have much hope for the baby, he survived and when he was four days old, a shunt was inserted, the opening in his spine was closed and his cerebellum was positioned. He had to stay in hospital for a long time. Today he cannot walk or talk; he cannot control his bladder or his rectum. He is able to crawl, but has no feeling in his legs from his knees downwards. "He is a very pleasant little boy, but he stresses when he cannot do what he wants to."

Suelene also has a daughter, one year and one week younger than her son. During her pregnancy, Down's syndrome was diagnosed, and although she was advised to abort the foetus, she decided against it - she had "this road to travel with a differently abled child, another one would not matter that much". Eventually the baby was born "perfectly normal", and is now two years old.

Moira is a nurse, and works night shifts. She has three children. Her second child was three months old when her husband died. After being a widow for seven years, she married an old friend. When she was forty, her third child, a son, was born. He is now fourteen years old. There were times that she doubted the wisdom of having this last child. He underwent various tests before he was diagnosed with dyslexia when he was in grade 6, and he is now attending a school for children with learning difficulties. What concerns her more, is his "don't care attitude". From an early age "he was a difficult child". When he was in grade 8, he experimented with dagga.

Moira's son has difficulty learning. She does not know whether he is "dense, or just plain lazy". Recently an educationalist referred him to a special school, but his teachers advised against this. It took him two years to accept the fact that he had to attend a school for children with learning difficulties, but now he has settled in, and is determined to matriculate at this school.

Cameron is also a nurse, with three children: Mark, the eldest, is eight and a half years old, and the youngest is five months old. Mark's birth was very traumatic, and Cameron was in labour for a long time. Although the abgar count was normal, and although several paediatricians could find nothing, she always had a feeling that "something was wrong with my child". She was accused of imagining things because of her medical background. However, the child "was difficult from the start", and resisted discipline. Eventually he was diagnosed with Attention Deficiency Hyperactivity Disorder. Shortly after the diagnosis, one Sunday, while she was working night shift, he climbed a guardrail in church, and fell one and a half storeys. He sustained head injuries, and "since then his hyperactive behaviour intensified". He has been attending the New Hope school since he was five and a half years old. Everything goes well, except for the fact that he "really has a problem with discipline, he cries very easily, and frequently throws tantrums".

Rina has two boys and a daughter. She married her childhood sweetheart just after graduation at university, and their first son (now nineteen) was born eighteen months later. She was in labour for 24 hours. There were complications and instruments were eventually used to deliver the baby. The umbilical cord was wound around his neck, which caused a lack of oxygen during birth. He was "a difficult baby" from the start. Aggressive behaviour tried to get the better of him. They consulted various doctors, and at the age of eight Tourette syndrome was diagnosed. When he was in grade 9, he became involved with drugs. When he developed more problems than usual at school, they consulted a psychiatrist, who recommended that they transfer him to a well-known private school. That proved to be the wrong move. Drugs were freely available, and the problem took on tremendous proportions. It was as if they "had thrown him into the lion's cage". At that stage Rina's husband became seriously ill, and her attention shifted to her husband.

When Rina's son started to threaten their lives, sell their belongings and damage the house during his aggressive outbursts, they realised it was time to take action, and had him admitted to a rehabilitation centre for drug and other substance dependency. There he was rehabilitated from the substance addiction, and he was converted to Christianity. He became a lovable, considerate and loving son. Everything went well for about nine months, but it soon became clear that he "had only changed one addiction for another – now religion had become his addiction". He slowly changed his religious views and started to follow a religious group whose prescriptions met with his approval. He underwent a metamorphosis. He has become "difficult" again, refuses to accept "no" for an answer, often "uses abusive language", takes his meals after the family have finished theirs and does not take part in any family activities. He openly condemns their Christian beliefs. At last they had to accept the fact that "this is the way things are and we have to learn to live with it".

Elrina also has three kids - two sons and a daughter. Paul, the eldest is seventeen years old. She describes him as "different - quite different". At one stage Tourette syndrome was diagnosed, but not enough of the symptoms were applicable to Paul to justify the diagnosis. She has to find an alternative for everything she wants him to learn in order to get results, as "the usual recipe for child rearing does not work for him". At times she suspected autism as the cause of his problems, but again he did not present enough of the symptoms to justify a firm diagnosis. Paul also suffers from dyslexia. He also has a serious eye condition, keratokonus, and a lens transplant is a definite possibility. Elrina also feels that he is emotionally not at the level one would expect from a seventeen-year-old. Paul experiences learning difficulties, and at present she teaches him at home with the assistance of a computer-based home schooling programme. In spite of all the difficulties, Paul is "a very gentle, loving person". He is also very artistic.

Gwynneth is 44 years old, and has four children: 17, 14, 10 and 5 years old. When she was four months into her pregnancy with her youngest son, she suffered a "tremendous emotional shock", and she was diagnosed with depression and hospitalised. Due to the pregnancy, she could not take medication. When the baby was three months old, she was again hospitalised. This youngest son experiences difficulties with auditory processing, and has a "handicap in his language development". He has also been diagnosed with Attention Deficiency Hyperactivity Disorder. He is very "moody" and resists discipline. About a year ago, a paediatrician diagnosed autism, but this diagnosis was questioned by two other neurologists. As a result of the lack of a specific diagnosis, finding a solution and "cure" for the problems are difficult.

These were the participants, and the stories they brought to the group. In the next chapter I describe our research journey, and how pastoral narrative practices were used to externalise the discourses informing the participants, the effect on their mothering practices, and the thin descriptions (White 1997:15) they formed of themselves as mothers.

## **CHAPTER 4: WITNESSING THE STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN**

### **4.1 INTRODUCTION**

It was our first time as participants to join in a group process discussing the suffering, the disappointments and the hope that have been part of our experiences of mothering our differently abled children. We all shared in the experience of "being a mother" in a Western culture, where mothers are profoundly affected by the myth of maternal omnipotence: good mothers are powerful enough to create healthy children, and bad mothers are powerful enough to create dysfunctional ones (see chapter 2). Mothers tend to share the notion of feeling worried, incompetent and inadequate when a child's behaviour does not follow the storybook version, or when her own feelings do not match the way she was told she ought to feel. She may think there is something wrong with her or her child. Either way, she tends to accept the blame and guilt (Heffner 1980:25). When mothering a differently abled child, these feelings are intensified.

We created witnesses to our stories in and by means of the group. According to Weingarten (2000b:392), "voice" is not "an individual's achievement of self-knowledge, but rather a possibility that depends on the willingness of the listeners that make up the person's community". Witnessing is therefore the "context within which voice is produced" (Weingarten 2000b:392).

By creating witnesses to our stories, the stories came into existence. "Without language, experience dissolves. Without language, experience cannot be shared and community cannot be formed" (Weingarten 1997a:49). We experienced that we talked ourselves and our stories into existence in the group (Davies 1993:21).

The group setting provided the opportunity to challenge the isolating effects of the marginalisation that the participants experienced as a result of ableist ideas in society. It helped mothers to develop initiatives for action to make their voices heard. Through the group discussions, the participants gave voice to what had previously remained unsaid, challenging the ideas of ableism in society.

### **4.2 COMMUNITY OF CARE AND SOLIDARITY**

The word "community" is threatening to become a "mere buzzword tossed about by one and all" (Gerkin 1991:117) and the search for community is becoming increasingly difficult. However, on our journey together we experienced something of community – we developed a "participatory connectedness" (Bishop 1996:23). We could not ignore the impact that the stories of the other participants had on our own stories.

In Gerkin's (1991:117) words, we dipped into "much of the deepest wisdom of the Judeo-Christian tradition".

For the first time we experienced the freedom of sharing our stories of mothering differently abled children with other people who were able to relate to and understand our experiences. From the first meeting onwards tears and laughter became familiar and welcomed companions. The pile of tissues became part of the standard preparations, as were the numerous cups of tea we absorbed. An intimacy – a sisterhood – developed through sharing what we truly cared about and found meaningful (Weingarten 2000b:391). In the safety and comfort of this "sisterhood", we were free to express ourselves without fear of judgement. Some of the participants even felt comfortable enough to use "taboo" words to express our feelings of frustration and anger.

The participants had never before had the opportunity to say what had been bottled up for so long. What they needed from our journey, were witnesses to their stories, compassion and a community of care. I was determined to follow an approach of power sharing in our meetings. Allowing the group to determine topics for discussion added to the sisterhood and intimacy that had developed since the first session. Respect for the uniqueness of each of the participants' stories was part of our group culture. We realised that what worked for one, would not necessarily work for another. As we shared our stories, we learned what we could from one another, respecting the uniqueness of each story.

During one of the sessions some of the participants vented their feelings of anger wrapped in humour. Elrina wanted to send her family to the moon! She was overwhelmed by frustration and anger because of the role forced on her as a mother. She voiced her feelings by saying, "The world is messing up things and I have to take pills!" I was keen to explore how this experience contributed to us forming a community of care and solidarity. In a letter following the session, I reflected on this experience by asking some questions:

*I wonder what it means to you to be able to vent your feelings the way you do? Does it say something about us when we are able to share our experiences in an atmosphere of acceptance? Could this be what we would expect from a "community of care" – to be able to vent our feelings in company of others who would understand our stories and listen in a non-judgmental way?*

In our last session, when the participants reflected on the research journey, they all voiced their appreciation for the "unwavering solidarity" (see paragraph 6.3.6) that they experienced in the group. When

we came to that last stretch of our journey, none of us were keen to end our group sessions. We decided to continue with our sessions on an informal basis (see paragraph 4.13).

At the beginning of the journey, I wanted the participants to talk about their own hopes, dreams and struggles. However, it soon became clear that their children were closer to their hearts – they needed to talk about them. Their personal experiences had been so interwoven with mothering that they had to talk about their children even when they had the opportunity to talk about themselves. Talking about our children took up most of our group discussions

### **4.3 COMMITMENT TOWARDS OUR CHILDREN**

Quite evident in our group discussions, was the commitment of the mothers towards their children and the sacrifices they all were prepared to make for the benefit of their children. Suelene told us about the animals they kept and how the children enjoyed feeding them. She narrated her trips with the children to the animals at feeding time and how she had to allow extra time for her son, allowing him to move at his own pace. She resisted the temptation to carry him, as she believed that he had to be motivated to use the little mobility he could master. She had to be creative in her ideas to keep her daughter from feeding all the animals before he arrived. The group commented on her patience and on the love we witnessed while she was telling this story.

The group also learned how Debbie sat for hours teaching her son to read. Elrina shared with the group her frustration when Paul withdrew from the family for days, refusing to participate in family activities. She referred to his behaviour as “passive resistance”. He excluded himself from loved ones, refusing to accept love and care from his family and missed out on opportunities to grow and prepare himself for his future. She was determined “not to give up on him. I will keep on trying – even if I have to force him to stop this self-destructive behaviour!”

Due to the effects of taken-for-granted truths convincing mothers that they were “not good enough” (see chapter 2), most of the mothers formed “thin descriptions” (Morgan 2000:12; White 1997:15) of their identities as mothers. I believe that alternative, richly described stories could reduce the influence of thin descriptions and create new possibilities for living. The opposite of a thin conclusion would be “rich descriptions” (Morgan 2000:15) of lives and relationships. The alternative story could be richly described by asking landscape of action and landscape of identity questions (Morgan 2000:60-62) and by exploring the meaning of incidents that contradict the thin description. I believe that the participants’ commitment to their children and the sacrifices they were prepared to make for the benefit of their children, were “doorways or



openings to new and different stories" (Morgan 2000:59). As a reflection on the meaning of their commitment and drawing out rich descriptions (Morgan 2000:69; White 1997:15), I asked some landscape of action and landscape of identity questions in a letter following the session:

*Suelene, the patience you are exercising while going through your days, making the most of each opportunity to help your son to develop his mobility and independence, is a source of inspiration to me. I cannot help but wonder where you have learned this patience? Do you know someone, your mother for instance, who set an example for you? Or was it something you had to learn? Of all the people you know, who do you think would be the least surprised to know that you have refined this ability to exercise patience when it takes you up to twenty minutes to cover the short distance to your backyard? And to make creative plans to keep your daughter busy so that some of the fun tasks of feeding the animals are left for your son?*

*What could it be that sustains you during the long hours of the day? I can visualise you reading stories to your son, pulling faces at him, changing your voice to imitate the characters in the stories. Where did you learn to do that? What does it mean to you that you and your husband are making all these plans to help your son to keep up as far as possible with the mobility of his sister? What does it say of your commitment to your son that you resisted the offer of the medical aid fund to buy a wheelchair and instead came up with other plans so that he could practise and improve what little mobility he has? Sometimes even at the cost of your own health?*

*You mentioned that the booklet "When mothers pray for their children" meant a lot to you. In what way did it help? Does it mean that when you pray for your child, you believe that you do not have to carry the burden alone, that Someone is there to help? Is it a source of comfort to you that God is walking this path with you and that you can share the responsibility? Are there more ways in which your religious beliefs and practices are supporting you?*

*Rina, when you told us about the incident when yet another aggressive bout of unfair accusations aimed at you took hold of your son, I heard that along with the pain you developed a certain amount of tolerance and acceptance of the situation. I wonder how you managed that? What strategies did you develop to assist you to cope with the situation? Are there people in your life who assist you with this or who have witnessed you coping with these incidents? Do you have a "well" from which you draw strength, like the well of living water the Bible speaks of? Did your journey take you through self-doubt and uncertainty to arrive at the conclusion that your son picks*

on you because he knows you are the one who will always be there for him, who will never reject him like others have done? I wonder what this idea or knowledge means to you as a mother? What does it tell you about your mothering practices? Who, of all the people you know, do you think would be the least surprised to know that you could manage to develop your own coping strategies to survive in the face of this ongoing unpleasantness trying to jeopardise the relationship?

Debbie, I respect the way in which you select the pieces that you can adapt and apply in your particular situation from all the advice you received during the years from therapists. Your action strengthens me. Thank you for this. You told us of positive experiences you had with therapists, of advice they had given you that you could use in your daily struggle in trying to find the best way to raise your son. I can imagine that it took some guts to adapt your own personal ideas in order to develop coping skills to handle your problems. How did you resist your own urge to help your son and instead follow the advice of the therapist not to help him too much with his schoolwork? Have you always had this ability to listen and adjust? Or did you have to learn it along the way? Where did you get the strength and the patience to keep on trying to teach your son the words he needed to make himself understandable? What happened to you when the therapist thanked you for your inputs? It was you who paved the way for her to unlock the words that were already present. You said that you always believed that if you worked hard enough and put enough into something, you would succeed and that if you worked hard enough, your son would get better. Yet you had to accept that you could control what happened to him or change his circumstances. How did you manage to make this mind-shift? What strategies did you develop to assist you on this path? I also want to ask you who of all the people you know, would be the least surprised that you were so committed and that you had developed all these coping skills? And yet also have enough to share with others?

Elrina, your commitment to your son is a source of inspiration to me – and I believe to all of us. I heard you say more than once that you would not let go – you would keep on trying to force him to stop self-destructive behaviour getting the better of him. However, I wonder if “passive resistance” is trying to convince Paul that if he keeps up this behaviour long enough, that you would step in and take over his responsibility again, leaving him without the stress and effort of doing it himself? I heard that “ultimate responsibility” is trying to convince you that you have to do it; that it is your responsibility not to give up. I wonder if the frustration of our situations is not sometimes trying to blind us, keeping us from seeing things in perspective; from discerning between the point where

*our responsibility stops and where our children must take up the responsibility for their own lives. I wonder how many times ultimate responsibility succeeds in twisting an admirable ability, like our commitment to help our children, into jeopardising their development of taking responsibility of their own lives. I wonder if there are some ideas in our culture about parenting that assist ultimate responsibility in this task?*

*I can relate to your desire to find a purpose behind the difficulties we experience. You said that you believed that God had a plan with this special child of yours – that you learned a lot about yourself, and that that was perhaps the bigger plan. What have you learned about yourself that you would not have learned if you did not have to deal with these difficulties? How and where do you find support? Are difficulties allowing you to ask for assistance when you need it or do they speak only of trying to do it on your own?*

*Gwynneth, I wonder how you manage to find time and energy to sit with your daughter while she read her lessons to you for hours, with four children, each one of them with their own unique needs? What could it be that propels us to keep going, keep trying to find new or exciting ways to help our children? What does it say about our commitment, our love for our children? I wonder where we find the time to attend to our own personal needs? Could it be that we are so involved with the needs of those who are dependent on us that we end up playing second fiddle?*

I wanted to consult with the participants whether they perceived these incidents as contradicting to the thin descriptions of their mothering practices. However, as usual they flooded the next session with more stories, sharing more experiences, way past the time limit we set for ourselves. I had to decide whether I was going to interfere and direct the discussion, or, according to my commitment to a power-sharing model, let them set the agenda for discussion. I consulted with the group about my dilemma and they unanimously embraced the opportunity to talk freely about their struggles, dreams and hopes.

Apart from the mothers' commitment to their children, what kept them going was hope. The way we were "doing hope" (Weingarten 2000b:402) together in the group was another particle of the cement that held the group together, adding to the solidarity we experienced in the group.

#### 4.4 THE GOLDEN THREAD OF HOPE

"Hope is something we do with others. Hope is too important – and its effects on the body and soul too significant – to be left to individuals alone. Hope must be the responsibility of the community" (Weingarten 2000b:402).

I marvelled at the golden thread of doing hope that was woven into all the group conversations. I wanted to make this more visible to the participants, and to link it with an emerging story of hope. I reflected on this in a letter:

*Can it be that we need those "glorious moments" (from the poem) (see paragraph 5.3.2) so desperately that we have learnt the skill to dig them up from their hiding places when we are running out of steam? Can the support and togetherness we experienced in a group like this be one method of strengthening our abilities to find and/or hold on to these glorious moments? Are there more ways we can equip ourselves to find or hold on to these glorious moments – to thicken and strengthen the golden thread of hope? Have you used the same or other strategies in the past?*

And in another letter:

*While I was listening to the tape-recording of our last conversation, the laughter and lightness with which you told your stories left an impression of marvel and awe in my mind. As in our other conversations, I heard two stories, though deeply interwoven: the story of pain and suffering and the story of hope and victory.*

During one of the sessions, Cameron reminded us of another golden thread – the moments our children tell us how much they love us, or that they appreciate all our efforts to make things easier for them. However, it seems that for some of us the burden of our daily routine and struggle becomes so heavy that we have difficulty in remembering the good times – the glorious moments. I wanted to build upon the alternative story of hope and victory and commented on this in the following letter:

*I wonder if this difficulty to remember the good times could be the work of guilt? Or could it be something else? Cameron, how did you overcome this when you decided that you would not allow the difficulties to rule your life? Even when guilt tried to convince you that God is punishing you, how did you manage to hold on to your golden thread of hope? Did you hold onto your God of love*

*– one who is not punitive, but loving and caring, a friend rather than an authority? How did you manage not to allow guilt to rob you of your peace of mind?*

Although helplessness and frustration sometimes tried to steal the sunshine from the participants, this golden thread of hope remained almost tangible during all the group discussions. This became evident when the participants wanted to light a candle of hope at our last session (see paragraph 4.14). Humour also played a significant role, adding to the coherence and solidarity of the group as we slowly but surely moved towards our alternative stories of hope and victory.

#### **4.5 HUMOUR**

Our group discussions were characterised by much laughter. It was as if Bosch (1979:73) had been informed by this group when he said that “fun and laughter are very close to sorrow and ... they may actually serve to help us digest the sorrow. Humor has a therapeutic value”. Humour also strengthened the group solidarity – as we cried together, we laughed together.

During the first session, when the participants introduced themselves, they told their stories of suffering and pain, wrapped in humour. Sometimes the laughter dominated the sorrow and pain. The story of suffering and pain only became clear when I listened to the recording of the session. I reflected in a letter following a session:

*While I was working on the summary of the session, I was once again under the impression of the suffering you all have to deal with on a daily basis. What touched me was that all of us keep going, hoping, believing and praying in the face of helplessness and frustration.*

*However, while listening to the tape-recording of the conversation, I heard that there was also lot of laughter. I wonder if you can remember the laughter, when thinking back to the session? Or was the impression left on your imagination that of sorrow and pain? Or a mixture of laughter and tears?*

I continued later in the letter:

*However, when thinking back to the session, I remember that Debbie said that one needed a sense of humour otherwise one would not be able to cope. Debbie, I wonder whether that sense of humour was there from the beginning, or did you have to gain it at a later stage? How did you*

*do it? Can you remember some incident when it particularly helped you through a difficult situation? Is this something that you had to learn yourself or did someone teach you this?*

*Rina, I noticed that you used humour and laughter while telling your story and I could relate to this. Do you think this ability to laugh in the face of so much pain and sorrow helped you through difficult times? If so, in what way did it help? Do you experience it as a benefit or do people sometimes misinterpret it as an inability to communicate the hurt? Could it be your way of showing pain that it will not get you down?*

Most of the participants have learnt to cope with their respective situations by focusing on the bright side. They adopted "laughing while crying" as an approach to cope with their daily portion of pain and sorrow, helplessness and frustration. Debbie especially developed this ability "to a fine art". When she told the story of Walter, the fridge and the bitten dog (see next paragraph), we shook with laughter. However, even though we enjoyed her "performance" telling the story, we could all relate to Debbie's feelings of frustration, helplessness and despair in the situation.

Here follows the story of Walter, the fridge and the bitten dog:

As a little boy, Walter developed an almost obsessive desire to open the fridge door and to position himself at the "floor" of the fridge, in front of the vegetable basket, sitting with his head in his hands and his elbows on his knees. After numerous efforts to distract the boy, (including playing with Legos that ended with Debbie playing on her own and the boy back at his favourite spot in the fridge) she was particularly frustrated one day trying to get the boy engaged in a game in the garden. The family dog, a Labrador, decided to help the mother by blocking the boy's way back to the kitchen door. All the dog got for its effort was that the boy opened his mouth as wide as he could and he bit the dog! It was a proper bite – Debbie had a hard time getting the dog's hair from the boy's throat as he choked on the hair and started to vomit. Debbie was still cleaning up after the mess in the bathroom, when the boy was already back at his favourite spot in the fridge!

Incidents like these reminded us that the behaviour of our children and our reactions to their behaviour affected the whole family as each member of the family reacted in a unique way to the challenges of the behaviour of our children.

#### 4.6 THE EFFECTS OF DISABILITY ON THE FAMILY

Even in our homes, we have some battles or struggles to face. For some of us, our children's fathers do not always agree with the way we care for our children. Debbie's husband accuses her of "always taking Walter's side", and that she is overprotecting him, while Debbie interprets the situation as always having to play referee between her son and his father. In Moira's household, the difficulties of her son sometimes bring discord between her and her husband. Cameron experiences issues of discipline becoming more complicated as she and her husband do not always agree on when and how to discipline their son. I reflected on some of these issues in a letter:

*Debbie's remark that she has to play referee between her son and his father, resonated with most of us. If this is so – that we experience that something is holding the fathers back to fully accept or live and work with the situation – what could this "thing" be? Could it be the difficulty to accept that a person living in the grown body might be emotionally and intellectually much younger? Could it be that guilt, sympathy, pain or our society's idea of what success as a grown-up person is supposed to look like, is trying to add to this difficulty?*

The interactions within our families are complicated by the special needs of our differently abled children. The group discussed the effects of the special abilities on the rest of the households' energy and creativity. Rina's experiences with her eldest child are blurring her understanding of her other children. She finds it difficult to discern between "normal teenager problems" and the "outrageous behaviour" of her eldest son. Elrina finds it heartbreaking to see how hard her youngest son tries to be "good" and not to cause her any problems, as "I have my hands full with Paul". Her daughter accuses her of spending too much energy on Paul and his needs at the cost of the rest of the household. Debbie fears the "Mommy Dearest" book her other children are going to write – they accuse her of forcing them to favour their brother in the games they used to play. She fears losing her other children, as she is always covering for Walter. They believe that because she has to spend more of her time and energy with Walter, she does not care so much for them.

Rina voiced the concern of the group when she said: "It seems as if we, the mothers, are the ones with the wisdom. When our children's fathers cannot understand what we are doing, they accuse us of favouring our children at their expense. Even our parents look at us for guidance – and then they question the guidance we provide! Somehow, we always end up in the middle."

Adding to our difficulties, the voices of taken-for-granted truths in the culture we live in are trying to convince us that we are not doing enough for our children.

#### 4.7 COMMON SENSE AND TAKEN-FOR-GRANTED TRUTHS

The thin descriptions the mothers in the group have of their identities are backed up by particular ideas, cultural beliefs and principles (see paragraph 2.3) – for example that there is a right and a wrong way of responding to a child and that mothers, when making mistakes, can do their children irreparable harm. These cultural ideas and beliefs are taken for granted (Morgan 2000:45) and perceived as “truths” or “common sense”. The term “common sense” refers to a commonly held understanding of the way life is or should be. “One simply knows what is right and what is wrong, and what is proper and what is improper, within that cultural tradition” (Gerkin 1991:54). This idea of common sense resonates with what Bruner (quoted by Weingarten 1997c:309) calls the ways in which “culture forms mind” (also see paragraph 2.3). All the participants could tell stories of how cultural and other voices – or discourses – convinced them that they were for example “not good enough”, and that they were ultimately responsible for everything their children did (Weingarten 1994:41-42).

Rina experienced feelings of discomfort when confronted with the “weirdness” of her son, as demonstrated by the loud clothes he chooses to wear, the colour of his hair and his hairstyle. Moira told a story of her son not “behaving properly” in church. As a result, she felt humiliated in the presence of her friends who witnessed this behaviour. Although everybody else could see the humour in the situation, she wished for the earth to swallow her at that moment.

In the following letter I touched on these cultural influences, making them visible, so that we could interrogate them and decide for ourselves whether we wanted to “buy into” these ideas, or develop our own preferred mothering practices.

*I wonder about the belief systems in our culture and how they affect us in the formulation of our own personal belief systems. How are we as mothers informed by these belief systems to accept responsibility for each and every thing that our children do? Why do we keep on disciplining them when they do not conform to what the “accepted” interpretation of the common sense of our culture dictates to us? Do we accept that individuality is something frowned upon by society? In what way are we influenced by the cultural and religious practices of the society in which we were raised? To what extent were we formed and shaped by these practices and ideas? Why do we feel responsible for our children’s every move? Moira, what is the effect of your mother’s saying, “Show me who your friends are, and I will tell who you are” in your feelings of responsibility*



*towards your son's choice of friends? Would you like to add something about what it says about a person when he or she shows care to people, nature or animals?*

Rina blames herself for helping the "system" to force her son into a role he is not willing – or able – to fit into. According to her own personal culturally venerated ways of being and thinking (White 1997:225), Rina initially believed all people should fit into two categories: the respectable, well-behaved people who prefer moderation in everything, and the "wash-outs". She never came across creative, "alternative" people, who are also "acceptable, proper" people. When her son turned out to be one of the "unknown alternatives", she did not know "how to handle him". The only way she knew, was to try and get him to be like her and all the other "respectable people" she knew.

Rina's desperation echoes in my own story. I feel that I did a lot of harm to my son for trying to "fix" him, to fit him into the "box" I believed he should fit into.

Cultural and other voices have convinced some of us that we dared not be too assertive and that we should avoid being labelled as "problem mothers". Debbie grew "hard and bitter" because she had to learn to stand up for her son's rights and for herself. I wanted to make these voices available for questioning and challenge, and asked a few questions in a following letter:

*Debbie, I wonder why you said that you had become cynical, hard and bitter. Strong words surfaced when you described yourself. Would you think that the word "assertive" could also be used to describe the way you have learned to stand up against the injustices of the world? Was that your way of asserting yourself against injustice? I wonder exactly what ideas in the culture we are living in are convincing us that we have to be docile and naïve? Where did we get it from that assertiveness and hardness go hand in hand? Why do we believe we have to feel guilty for the fact that we have learned to stand up against the world to protect our children?*

We realised that some of these common sense knowledges promote feelings of guilt.

#### **4.8 GUILT AT WORK**

Freeman, Epston and Lobovits (1997:78) refer to "guilt and blame that circulates around parenting, particularly around mothering, in our culture". According to Heffner (1980:24-25), "feeling guilty" is a normal condition of motherhood. Guilt is the inevitable outcome of the three major messages that have been communicated to mothers about child rearing:

- A good mother will think first and foremost about the needs of her child.
- Great harm can come to a child if her or his needs are not met properly and mothers have great potential for damaging their children.
- There is a right way and a wrong way of responding to a child and if the mother makes a mistake and does it the wrong way, she will irreparably ruin her child.

Against this background, it is no wonder that mothers are prone to self-accusations that are informed by "mother-blaming" (Freeman, Epston & Lobovits 1997:78).

Since the first session, the voices of guilt have been prominent in the group discussions. In the letter following the first session, I used externalising conversations (see paragraph 3.2.5), separating our identities from the feelings of guilt we experienced.

*Certain practices are on the side of guilt, instigating guilt and maintaining it. Guilt is on the lookout, trying to find something to hold us accountable for. Was it the work of guilt and responsibility wanting to*

- *convince Debbie to react to the therapist who said to her, when handing her baby to her, "What will become of this child, is now in your hands";*
- *make Moira wonder if her working hours have an effect on her son's lack of interest in religion;*
- *recruit Rina into thinking that if she was older and more mature when her son was born, she would have been able to take better care of the difficulties;*
- *make Cameron believe that because she is in the medical profession she should be able to fix everything, especially as her field of expertise is intensive care?*

The voices of guilt appeared in most of the group discussions. These voices were intensified by incidents where the mothers, at their wits' end, acted against their own better judgement (see White 1997:41). After the episode with the dog, Debbie gave her son a hiding out of pure frustration. Rina, convinced that it was her responsibility to get her son to conform to the "common sense knowledge" that "one has to sit still in church", pinched her son when he found it difficult to sit still for the duration of the sermon.

The effects of guilt in her life saddened Rina. She said: "What concerns me of this whole thing of guilt, is that I only remember the bad things. My mind has become like a stuck gramophone record. I have to make

a conscious effort to remember the good times, or even the behaviour that triggered these actions I am now so ashamed of. And the worst thing is, I know that he uses that against me to manipulate me." In the letter following the session, I wanted to make visible to the group the taken-for-granted truths that supported and sustained the voices of guilt. I moved away from thin descriptions to more richly described alternative stories.

*When Debbie gave her son a hiding (the story of Walter, the fridge and the dog), guilt reminded her of the psychologist who told her once that all a mother's hands should be used for, is to express love. Guilt also tried to convince Rina that she had to respond when her son accused her of being a rude and an unloving mother, as she pinched him when he did not sit still in church. Rina, was the voice of guilt so strong that although you knew that your son was trying to manipulate you, you found it hard to escape? What gave guilt the power (audacity almost) to clog your memory so that you could not remember the provocation leading to your behaviour, in order to defend yourself?*

*I wonder whether guilt and the criticism, which we have to face regularly, sometimes join forces to convince us that we are guilty as charged, leaving us defenceless. Even obvious defences, like the fact that we have other "normal" children, are not strong enough against the persistent voice of guilt. I also wonder whether it could be the voice of guilt that is trying to obscure the good times? And I wonder what allies guilt has gathered, assisting it on its devastating path? Can you think of any? I wonder how much it counts that we have helped our children to adjust and become members of a community? Haven't we taught them personal hygiene? Haven't we taught them good manners (that they sometimes even remember)? Haven't we taught them about God and God's love and presence in our lives?*

Guilt tried to convince Rina that she was a bad mother. "If I were more patient when my son was little, things could have been different. I shouldn't have pinched him when he did not want to sit still in church." This voice of guilt was overshadowing and silencing alternative voices of care, love and other forms of availability.

Guilt also tried to convince Gwynneth that she was instrumental in her son's difficulties as she had experienced emotional and health difficulties during her pregnancy. "Because he was part of my body at that stage, he did not have a choice but to be a part of my struggle."

In the following letter, I challenged the voices of guilt by "panning for gold" (Wylie 1994), meticulously prospecting for ideas that could contradict the dominant story of "I am guilty".

*As we are sometimes so defenceless against the voices of guilt and so willing to take up the burden of guilt for everything that goes wrong, I wondered whether it would help to strengthen our golden thread of hope, to assist us in resisting the onslaught? Can we discern between feelings of responsibility and guilt? When is something our responsibility and when does guilt want to dump something on us that does not belong on our shoulders?*

*I wondered how Gwynneth, Elrina and myself, who had suffered emotional stress during our pregnancies, managed to stand up against the voice of guilt when told by doctors that our emotional stress at the time added to the problems of our children. Gwynneth, how did you manage to stand up against the voice of guilt? What did you do to acknowledge your feelings of empathy with your child? How did you use your struggle against depression to strengthen the emotional bond between the two of you?*

Sometimes guilt succeeds in blinding us to the "glorious moments", the positive aspects of our children as well as our "successes" as mothers. I reflected on this issue in one letter:

*I wonder how guilt succeeds in blinding us to the positive aspects of our children as well as our mothering practices that we can feel good about? I wonder what allies guilt has gathered in its efforts to convince us we have to feel guilty for almost everything we do or do not do. Can you think of any? Moira, you told us of a lot of admirable things your son did – that he cares for you as well as for other people; that he is not the tough customer he pretends to be; that he appreciates your reminders that you will not stop praying for him; etc. You also told us of the remark made by your friend, that she respects you for your patience and endurance regarding the way you react to your difficulties. You said that you felt good about yourself as a mother due to this remark. I wonder what it is that convinces us to bury these incidents so deep that we need to have to search for them? Could it be something in our culture that convinces us that we are not allowed to feel good about our mothering practices, or even about ourselves? Do we have to wait for someone else to tell us that we are not that bad? Why is it so difficult for us to talk about our successes as mothers?*

Some of the participants concluded that the voices of guilt we are so willing to accept are being used against us in various ways. Debbie complained about the marketing of educational toys – we have become a “cosy moneymaking racket” for the marketing world. Guilt tried to convince her she was “bad” as she was not able to buy all the educational programmes her son “ought to have” to help him with his development. We are not informed about the less costly alternatives that are equally effective, if not more so. Suelene told the story of the walking frame her son needed. The first quotation was R5 000. She eventually bought a similar item from another supplier for R399. Following the conversation, I commented on this issue in a letter to the group:

*The feelings of guilt that are almost part of the package deal of motherhood and which are intensified when our children are differently abled, are used against us in the marketing of products like educational toys. Debbie, I related to inadequacy and guilt – and anger – trying to get a hold on our lives for not being in a position to buy all these wonderful products with all the wonderful promises of instant results for our children.*

*I wonder what values and ideas in our community inspire marketing people to exploit our vulnerability into tricking us to believe that we have to buy these products, or else we fail our children? On the other hand, could it be “guilt” trying to trick us into believing this? Could it be “guilt” trying to blind us, to cloud our perspective so that we find it difficult to recognise the exaggerations of sales talk? What values in our community allow the voices of sales talk to be heard so much louder and clearer than the marginalised voices of those who try to inform us of the real value of these products, or even alternative methods of stimulating our children without spending money? The small voices of care, laughter, cuddles and other ways of showing our love are silenced by the overpowering voices of the marketing world and our tendency to collude with these voices.*

In the company of guilt and other taken-for-granted truths such as ableism, success and intolerance for differently abled people add to our concern for our children's future.

#### **4.9 CONCERN FOR THE FUTURE OF OUR DIFFERENTLY ABLED CHILDREN**

Participants with older children were gravely concerned about their children's future and discussions on the future formed a substantial part of our group meetings. One of the issues we discussed was when our children would be ready “to leave the nest”. We wondered about our own perceptions and to what extent we were blinded by “what it takes to make it in this world”. We asked: “Are our children not ready to leave

the nest, because we perceive it that way, or are they really not ready?" This was a contentious issue that intensified with the introduction of the different abilities of our children. Reflecting on this issue, we asked the following questions: Are we overprotecting our children? Will they learn to stand on their own feet if we grant them more opportunities to practise? Is Rina's son not interested in getting his driver's license, because she is still willing to take him where he wants to go? Is she protecting him – and the community – by not encouraging him? Is he ready to take on the responsibility? His behaviour shouts out loud and clear that he is not – but how is she to know that he will change if granted the opportunity? How are we supposed to know these things?

In a letter I summarised our session and reflected on this issue:

*For those of us who have older children, the future of our children is an area of great concern and worry. When they approach the age where they are supposed to leave the nest and start on their own life's journey, helplessness would tend to overwhelm us and tell us that they are not prepared for the journey, or even question us whether we have done enough for them. I wonder whether this is not an unfair situation, adding more to the burdens we are already carrying?*

Debbie was concerned that in the "real world" others would not be willing to make the same sacrifices she and her family were willing to make and that Walter would find it difficult to adapt as a result. Her fear was that she would be responsible! We wondered whether we were not standing in their way to independence. The issue of how we are supposed to prepare our children for the future was discussed at length in one session.

Some of the remarks made by the participants on this issue were:

We are doing all we can to prepare our son for an independent life. He is, however, not co-operating and we are stuck with him. Will I be responsible for him for the rest of my life?

I admit that I am afraid to let him go, but I am concerned that he will not be able to make it.

I sometimes wonder whether I don't stand in his way to independence. Perhaps he will be able to make it. Who decides he will not be able to cope?

Do we have to wait until they give us the cue that they are ready to go? What if they enjoy the comfort of being cared for and are therefore not motivated to spread out their own wings? Are we protecting them against the pain we ourselves experienced?

After all the years of being belittled by the school system, our children do not have the confidence to walk into a job interview with an attitude of "you are so lucky to have me!" They would rather crawl into the interview and apologise for the fact that they attended a school for children with special abilities.

An outcome of our group conversations, discussing the pain and sorrow of our lives, was that we wanted to acknowledge the extent to which we have kept alive the hope that things would be different in our lives. Some of our conversations contributed to an acknowledgement of our "persistence in acts of resistance despite formidable odds" (White 1997:142).

#### **4.10 RESISTANCE TO THE VOICE OF GUILT**

During the eighth session, Moira and Rina voiced anger at their situations. In the following letter, I tried to elaborate on these acts of resistance, thickening the unfolding alternative stories by making it visible to us, encouraging us to escape the web that guilt tried to weave around us.

*Moira, you said that you were angered by the memories coming back to you while you were writing your spiritual journey. Selfishness convinced your son that it was "his birthright to keep on receiving, without putting anything back into the relationship". Selfish behaviour (is this what you would call it, or can you think of another name?) was trying to disrupt the whole family. Even the relationship between you and your husband did not escape the onslaught. You also mentioned that your whole life is planned around your son and his needs – your holidays, your money, your professional life, everything. Whereas your daughters would sometimes put something back into the relationship by means of little notes or letters, expressing their thanks for your commitment to them, your son would never do anything like that. I wonder if you would call this anger you are experiencing now, a form of resistance to selfishness and its effects on your life and family? I am curious to know whether this resistance is helping you in any way? If so, how does it help? Do you think "resistance" will change anything in your situation? If so, in what way? Do you think it is a good, a bad or an in-between thing? Do you think this will affect your family life in future? If so, in what way?*

*Maira, you said that a mother does not need to be clever, pretty or important, or have a beautiful body. She only needs the ability to pray. I am curious to know how this ability to "pray" is helping you being the mother you want to be. I wonder if you experience God as an "ally" against selfish behaviour?*

*Rina, you told us that you decided to no longer allow guilt to dictate the terms of your relationship with your son. Guilt tried to convince you for some time to believe that you were responsible for the problems your son was struggling with. Guilt used manipulative behaviour to seduce you to believe that you, by encouraging your son to take the medication prescribed by professional people, helped him onto the path of drug use or abuse. I wonder if guilt gathered more allies to try and convince you that your parenting style was adding to your son's problems; that you used the "wrong" techniques to discipline him when he did not conform to the values of the rest of the family and community. How did you silence this voice?*

*Rina, I heard another voice on Saturday – that of resistance. The voice of reason (or would you call it something else?) became stronger and started to out-manoeuvre the voice of guilt. Would you say that reason reminded you of all the sacrifices you made for your children – that your whole life was planned around their needs and to accommodate them? You cared for them in every small respect – you even took something warm to wear on a cold day to school. They never had to walk home from school – you were always there to pick them up. And this son was one of them. You did not leave him out in the cold – he was part of this warm, safe shelter you provided for your family.*

*You said that you realised "he is what he is – not because I made him like that". He made some choices and you were not prepared to accept responsibility for the choices he made. You added that you would no longer accept the idea that "every finger points towards Mother!"*

*I wonder what it was that enabled you to listen to the voice of reason? You said a combination of circumstances led to the catharsis that happened last week. You said that among others, the discussions we had in the group added to your strength to take this stance against abusive behaviour. I am curious to know in what way did it help? I wonder what the effect of this stance you took would be on the future of your family life? How would the knowledge "I am not a bad mother" that is once again available to you, influence you and your family life in future?*



Apart from guilt that tried to make our lives miserable, the ideas of ableism in the community served to add to the sorrow and pain of our lives. During some of the group discussions, we voiced our anger at the situation, refusing to accept this as the "truth".

#### 4.11 RESISTANCE TO THE VOICE OF ABLEISM

We believe that although many of our "square eggs" are talented, they become sidelined, as their unique talents do not fit the expectation of what is considered "normal" for the rest of society. We want to know how these parameters are defined and by whom. We wanted to know: "How is it that a girl with spiky green hair can pass for 'normal', but a young man with an askew hand and a foot that does not function properly, cannot pass the test for 'normalcy'?" Because our eggs are square and not the "normal" shape, they do not "fit" the standard for performance at school and they have to undergo one form of therapy after the other. Moreover, when therapy fails, they are sidelined from the mainstream to special schools and later on to places providing sheltered employment. We wonder to what extent sayings like "beauty is the gold coin of human worth and intelligence is the silver" created the perception that our children are worth less than the beautiful and intelligent children, enforcing ideas of ableism. We want to know where sayings like these come from and how they fit into Western cultural discourses like growth, achievement and success?

I reflected in a letter to the group:

*Could it be that society would wake up sooner or later and realise that our "square eggs" have lots to offer, if only they are given the chance? Are we creating castles in the air when we dream of the day that society will no longer be blinded by the discourse of growth, success and profit and for once recognise these square eggs for the value they have to offer? When will society acknowledge its tunnel vision and realise what it had missed all the time? Can we dare to hope that that day will come soon so that we can stop worrying about the future or our children? Is there anything we can do to speed up this process?*

In our daily struggles we become tightly bound to those forms of life and thought informed by the "truths", constitutive of the "grand narratives" of human nature and human development (White 1997:227). One such "truth" that we are confronted with, is the idea of ableism. "Rugged individualism (the loner hero)" and "self-reliance" are two more such "truths" identified by Combs and Freedman (1999:27). Together with the increasingly heavy emphasis on individualism, strengthened by Margaret Thatcher's declaration that "there 'is no society', only individuals and their families" (Speedy 2001:25), these "truths" add to the reality that we have to fight our battles alone and privately, with very little help from our faith communities.

We realised that we had to face realities that were draining our energy. As we were “trained” to be “selfless caregivers”, some of us found it difficult to attend to our own personal needs – to take care of ourselves.

#### 4.12 SELF-CARE

Most of the participants tried to live the precepts of the twisted cultural discourse about motherhood: “good” mothers are selfless and “bad” mothers are selfish. Appropriate self-care did not fit into this dichotomy and so became an activity to which mothers could only aspire (Weingarten 1997a:44).

During one session Gwynneth told the group about the few days she spent without her husband or children in the company of her sister and her parents. Although it was not a “pleasure trip”, she had time to enjoy the sea and her sister’s company. She was amazed when she realised that she was at times thinking about her children, but not about the fact that one could not read and the other could not talk. She enjoyed her “freedom”. It was “an eye-opener to realise I can actually enjoy myself apart from my children”.

I wanted to centralise these ideas in the following letter:

*Gwynneth, I wonder about your amazement at this discovery. What in our culture or society seduces us into believing that we can only be “whole” through our children? Do you think that this “revelation” will change your life? If so, in what way? Can you think of a way in which you can celebrate this discovery? Is that something you would like to do? Is there any other way in which you can build upon this new side of yourself?*

Debbie referred to an incident one Friday night when she insisted that her family stayed home with her. The difficulties she had experienced during the day had drained her strength and she needed the comfort of her family.

I reflected on the above-mentioned incident with landscape of identity questions:

*Debbie, what does it tell you about yourself that you can take a stance like this? What does it tell you about your family that they were prepared to support you? You said you were always the one to make sacrifices to accommodate them and that you believed it was their turn. Do you think that this was an act of resistance? Do you think you stood up against the idea that mothers should be “selfless” and always put their children and families first? Can you think of other times when you*

*stood up for yourself and demanded to be cared for instead of doing the caring? You said that sometimes you felt as if your efforts disappeared into a bottomless well. Do you think taking opportunities to care for yourself will help to close up bottomless wells? Can you think of other ways to care for yourself? Can you think of a way to celebrate your ability to take care of yourself?*

Moira mentioned that guilt always tried to convince her that she was a "bad" mother when she experienced "feelings of relief" when her son was visiting a friend. She even celebrated her "freedom" one day her son decided to run away. When he left with his suitcase, she enjoyed a well-deserved rest with a book! I reflected on this in the following letter:

*Moira, when you said that you needed a "gap", were you implying that you needed time to care for yourself? You said your son takes up the effort of six children – you are always "putting out fires" when he is around. You said that you are relieved when he is visiting a friend and you have time for yourself. Yet guilt is trying to convince you that it is "bad" to feel like that. I wonder where guilt got that idea? Could it be coming from the same cultural ideas we are raised with, that a good mother should be completely selfless? Do you think it could possibly be a fallacy? I wonder how it will be for you, if you could stand up against guilt and show guilt that you will not succumb to this fallacy?*

Like Greenspan (1998:38) we experience that mothers of differently abled children are marginalised largely through being invisible – an invisibility that is both part of and distinct from the social invisibility of differently abled people themselves. It is like living in muddy waters, far from the mainstream, or like voices crying in the wilderness.

#### **4.13 VOICES CRYING IN THE WILDERNESS**

For some of us, the burden of mothering a differently abled child is like voices crying in the wilderness. Debbie described her experience: "I had to take Walter to so many therapists. I am tired. I am drained of all my energy. My physical strength is not up to it any more. Vitamins do not help either. A child with a visible disability is being treated as if he is not worth as much as other children."

She continues: "'There's no rest for the wicked', the saying goes, and you ask yourself what have you done that's so wicked that even when you've put in twice the amount of effort for half the results, you still fall short so far."

Debbie was for the first time confronted with the reality of her son's "differentness" on his fourth birthday. She had to buy a present and while she was standing among the toys, she picked one that needed two hands to operate. Suddenly it dawned upon her that her child would not be able to play with that toy. That incident opened the floodgates of tears for her son.

The day (fifteen years later) when she warned her son to fasten his seatbelt "so that you will not get hurt", and he replied, "So what – I am already hurt", was the day she used up the last of her tears.

Maira cannot get used to the pain. Every time something reminds her of her son's difficulties, her stomach turns. She cannot – and will not – develop "calluses".

We shared in each other's stories and along the way formed a strong sense of cohesion and solidarity. We appreciated the strong bond between us, as it offered us a safe space to be – more so in the light of the absence of support from our faith communities. None of us wanted to let go of the safety and the comfort that we experienced in the group. Therefore we decided to continue with the group sessions on an informal basis, creating our own community of faith. We felt something like the lepers of biblical times who were living outside the community and had to fend for themselves.

For the final "destination" on our research journey, we planned a ritual. For all of us, this idea was also a "first".

#### **4.14 RITUALS AND SYMBOLS**

Rituals are "co-evolved symbolic acts that include not only the ceremonial aspects of the actual presentation of the ritual, but the process of preparing for it as well" (Imber-Black, Roberts & Whiting 1988:8). Beyond action, rituals have available to them the "density and multivocality of symbols" (Imber-Black, Roberts & Whiting 1988:12). Symbols can hold multiple, disparate meanings as well as describe what cannot be expressed economically in words. Rituals may provide a way for people to find support and containment for strong emotions. "The telling and performance of alternative stories in rituals can be transformative" (Morgan 2000:114).

According to Ikeler (1990:236), a child with a disabling condition "represents death – the death of anticipated joys and hoped-for vicarious fulfilments". Following the occurrence of disability, the child that parents had imaged at different ages and in various roles, no longer exists. Therefore, the family experiences all those emotions that characterise bereavement over an actual death. Only, in the case of

disability, the bereavement is chronic. When someone dies, religious and social rituals support the family members. These rituals provide friends and neighbours with cues as to how to express their sympathy. Unfortunately rituals that would support people bereaved by disability do not form part of our way of life. Thus family members are "left on their own as they attempt to live out and put behind them their tragic loss" (Ikeler 1990:236).

We were unable to find anything more meaningful than a ritual that would describe and acknowledge what we have experienced as a group. We felt a sadness that we had to invent our own ritual, among ourselves, in the absence of support from our faith communities.

Our ritual symbolised the bereavement and "death" of our images of "normal and healthy" children that no longer existed. However, the participants did not only want to focus on the "problem" side of the story, but also include the alternative story of hope for the future. We decided to include symbols of celebration of the "new" child we received in the place of the one we lost, as well as symbols of the hope we had for the future. We agreed that each participant should choose and prepare her own ritual according to her own needs.

Suelene and Debbie prepared a rose with a piece of paper attached to the stem for each participant. Each participant was asked to write down her expectations of the future. The roses with the dreams were then sealed in a bottle, to be opened one year later. At a reunion of the group, we would open the bottle and the group would have an opportunity to reflect on our expectations. The participants were enthusiastic about the idea, and participated in the ceremony of writing down their dreams. Suelene sealed the bottle and promised to keep it until the reunion.

Maira wanted to bury that part of her life reminding her of the teachers who called her to complain about the behaviour of her son. She lit a candle in the hope that through the work of the Holy Spirit her son would change.

Suelene bought a jar for each member of her family. In her jar, she put her thoughts, her dreams, her feelings, her hopes, her ambitions, what she wanted for herself. In the jar of her son, she put her hopes for his future. She lit a candle for the hope she has for her son; that the attitude of ableism would change and that he would be accepted by society and that her mother-in-law would learn to accept her son. She planned to open the jars in about ten years' time.

Debbie wanted to let go of a few of her dreams:

- Her dream of making Walter's hand and foot function normally. She really believed that with faith and hard work she could "fix" him. "It was terrible to face the fact that nothing was really going to make that big a difference to who he really was.
- She also wanted to have "an organised, secure, peaceful environment with no ripples on my little ocean. Ha, ha! There is always a crisis when I'm least in a position to handle it".
- She has to let go of her dream of doing something big and positive to change the world and instead make the world around her positive for those closest to her.
- Her dream of making Walter happy and accepted in this world has to be discarded.
- Mostly, she has to discard "the guilt that his handicap is my fault and know that whatever I may feel I have done wrong, the will of God will ultimately prevail".

She wrote these dreams on a piece of paper and burnt it ceremoniously.

She lit a candle for her hope for the future of her son – that he will be happy and able to live an independent life.

Gwynneth wanted to admit to her children, in particular the youngest one, that she was not as available to them as she would have liked while she was hospitalised shortly after her youngest child's birth. She lit a candle for the potential she knows her son has. Her hope for him was that he would be granted the opportunities to realise that potential.

Cameron wanted to write down her "bad memories" of experiences with doctors, her family and friends, put it in a balloon and set it free to go as far away as possible. She wanted to light a candle for the hope she has for the future – that she would be able to learn from her mistakes – to grow in wisdom. She wanted to concentrate on a positive attitude. She also wanted to light a candle in acknowledgement for the support of her husband and friend.

I did not want to burn or bury anything. I wanted to light a candle of gratefulness for what I have learned from the group and the way my story changed through sharing in their stories. I also wanted to acknowledge my appreciation for the kind of person my son is and what he taught me about himself as well as about myself.

Rina wanted to discard symbolically the idea that “I was a bad mother”. She wanted to burn her feelings of guilt. She lit a candle of hope that her son would be safe in the hands of God and that he would be touched by the Holy Spirit. Perhaps one day, he would come back to her, prepared to receive the love she was so willing to wrap him in, if only he would allow her the chance. She was also going to light a white candle each time despondency or despair would try to steal her sunshine, as a reminder of the hope we were doing together.

Each participant took a seedling with her to plant as a symbol of the growth we experienced on our journey together, the love of God and the hope we have for the future.

Thinking back of the group discussions, what stands out for me is how important the group sessions became to the participants. For me, it uncovers the absence of the faith communities in the struggles of these mothers, specifically concerning our differently abled children. The way we were “doing hope” together in the group, accentuated our need for support from our communities of faith even further.

In the next chapter I firstly discuss pastoral care for families with disabled children and secondly I discuss our contribution to competent and communicative action to bring about a change in the situation of differently abled people and their families – our contribution to “doing theology”.

## **CHAPTER 5: PASTORAL CARE FOR FAMILIES WITH DIFFERENTLY ABLED CHILDREN**

### **5.1 INTRODUCTION**

The history of the church's interaction with disabled people is at best an ambiguous one. I refer to "church" as an umbrella concept for the full diversity of denominations, taking into account their diversity and that exceptions to the generalisations do exist. Rather than being a structure for empowerment, the church more often has "supported the societal structures that have treated people with disabilities as objects of pity and paternalism. For many disabled persons the church has been a 'city on the hill' – physically inaccessible and socially inhospitable" (Eiesland 1994:20).

The intolerance differently abled people are experiencing (for example the two nursery school boys who wanted to kill the boy who was different from them – see paragraph 5.5.1) reflects the values of prejudice and bias toward people who are different from the mainstream. This intolerance reveals the "community's underlying values of discrimination and marginalisation of those who are 'different' from us" (de Lauwere 2001:186). It reflects an attitude of excluding those who need assistance and care from the mainstream. However, Christian values may drive people to care for disadvantaged people "in a gracious manner, but we still desire to do so by isolating them and keeping them 'where they belong'" (De Lauwere 2001:186). In doing so, we keep them marginalised, discriminated against and therefore disempowered, invisible and voiceless. Invisibility and voicelessness are terms common to feminist and liberation theology, indicating "the condition of those whose presence or opinion has no real influence on the decision-making structures which affect their lives" (Soskice 1996:112).

Families with differently abled children tend to "drop out of church and the reason might be the stigmatization they experience there" (Ikeler 1990:239). In the next few paragraphs I discuss the group's firsthand experiences of intolerance and marginalisation.

### **5.2 THE SILENCE OF THE FAITH COMMUNITY**

As all the women in the group were followers of the Christian belief system, the church and our faith communities were part of our lives and our experiences. For some of us our faith was a source of support and strength. For others the picture presented by the church and faith community did not tally with reality as we experienced it.

Debbie frequently consulted her pastor and most of the time she experienced him as sympathetic. However, the advice she received was not helpful. It did not help her to be told that "the heavier her burden



on earth, the bigger and brighter her crown in heaven" would be. She was quite willing to accept a smaller crown in heaven, could she have some relief of her burden now!

Once she consulted a pastor about the friction between her son and his father as she experienced difficulty in her role as referee between the two of them. She complained that the burden of raising a cerebral palsied child rested on her shoulders alone and that she felt lonely and burned out due to lack of support from her husband. However, she was advised that she had a choice: either she divorced her husband or she had to institutionalise her son. Blinded by the discourse of patriarchy that perpetuates a system of male domination at the expense of women (Grobbelaar & Kotzé 2001:90), the pastor did not even consider the alternative to advise her husband to support his wife and take on his share of the burden of caring for his child. Debbie decided not to take this advice and that was the beginning of what she called her process of developing "a hardness, a shell to protect herself" from the pain.

Baptismal vows resulted for Moira in a source of guilt and pain. Guilt was trying to convince her that she is to blame because her son was resisting the family values and behaviour she was trying to teach him, like going to church and attending Sunday school. She took the vows she made at his baptism seriously and believed it was her responsibility as a parent to bring up her child as a God-fearing believer. Should he not behave, she feared that she would have "some explaining to do at the gates of heaven".

Rina considered attending church on Sundays as something that she had to do to feed her soul for the week. Participation in church activities provided a community of care that carried her through difficult times. However, her reality of being a mother of a differently abled child was excluded from the care she received. The role the church played in her life was that of a "filling-station" (Kotzé 2001), where she was "filled up" with renewed strength to go back to face her difficulties on her own. The church cared *for* her, not *with* her.

Going to church became a burden to Suelene due to the physical difficulties she had to overcome. The church building was not easily accessible and she and her husband had to carry both their children. She added: "I was feeling self-conscious – it was as if everybody was looking at me to see what I was going to do next." Sometimes it was "easier to stay at home".

### **5.3 SPIRITUALITY**

In a study that formed part of a larger investigation of parent empowerment in families with differently abled children, Bennett, Deluca and Allen (1995: 309) identified prayer, church attendance and several specific religious beliefs as sources of support for these families. They identified religious beliefs and practices as

supporting hope and as strengthening a parent's ability to cope - as was the case with Rina for whom the religious practices provided a community of care. Bennett, Deluca and Allen (1995: 309) indicated that religious beliefs contributed to the parent's sense of empowerment and confidence in her/his ability to create a happy future for the child. However, they added that "religion may not necessarily be supportive and may even be a source of stress for some parents" (Bennett, Deluca & Allen 1995: 310) – as was the case with Debbie. The confusion and isolation some of the participants in this study experienced reminded us of "voices crying in the wilderness". Some of the members of our group journalised their experiences. In the following paragraphs, I share snippets from their spiritual journeys.

### **5.3.1 A spirituality for voices crying in the wilderness**

Debbie was confused by the different ideas she was confronted with. The neurologist assured her that her son's disability was not her "fault" as she was not God, which implied that God should be responsible. In church she learned it could not be God as "God only gives good things to his children". Debbie wanted to know what she did wrong. She believed that God did not need to take such extreme measures to get her to listen – "He only could have asked and I would have listened". She was always close to God and in her opinion she was an "obedient child". At times she even bargained with God: she was willing to accept a lesser crown in heaven, if only God would ease the pain now. She figured it out for herself: She could not fix it and God did not want to fix it. She kept on praying, even though she doubted the point of praying, as God was not listening any way. Eventually the "disorientation" (see paragraph 5.3.2) passed and her faith reached a different, a deeper level. She reached a "new orientation". She knew that "had God not loved me and been with me and my child, the outcome would have been so different. I can look back and see where God was present and how He helped me". However, she still had difficulty in finding the purpose behind her suffering.

For Debbie it was about acceptance. The obstacle in her way to acceptance was her desire to be in control. If she was in control, she could have mended her son's hand and foot and all the other difficulties by working very hard. She was prepared to do that, but unfortunately "the worst was to accept that he was not going to get better, no matter how hard I worked!"

Eirina had to learn patience from her experience. She found comfort in the belief that there was "a plan with this special child. I have learned a lot about myself – perhaps that was the bigger plan". Her son's strong religious inclination was also a source of comfort to her.

Suelene found comfort in prayer. She managed to put her child in the hands of the Almighty God. She knew He was always listening, and accepted His decision not to always answer her prayers right away – she was prepared to wait for His time. Although she asked “Why me?” she never reproached God. Her motto was “It does not matter how hard you fall; what matters is how fast you can recover”. She experienced God’s presence, even in her suffering.

Rina found strength in the care group her family was part of and in a personal relationship with God. “It was this relationship with God that had carried us the past six years when my son became involved with the wrong friends, started lying, smoking at thirteen, selling our things to buy drugs, swearing, threatening to kill us, experimenting with occult-related things, expressing his hatred towards us. It was our relationship with God and the support of fellow Christians that carried us during my husband’s operation and treatment for cancer. It was this relationship with God that carried us through financial difficulties. By placing our complete trust in God to carry us through many difficult times and constantly praying, we have overcome many things.”

Although Rina puts her trust in God to take care of the problems with her son, she sometimes wants to ask Him to “hurry up”. However, she believes that “God has given us the strength to carry on”. She eventually reached the point where she could ask: “Why not me?”

Rina concluded her spiritual journey: “Our path of life has indeed become more difficult in some ways, but had that not been the case, I may never have longed for God’s presence in my life as I do now. God has become Friend, Father, Confidant and most of all, Hope to me.”

Maira learnt through her experience to have compassion with other people who were experiencing difficulties. The difficulties with her son “keep me permanently on my knees”. She has learnt that “a mother need not be clever, pretty, important or have a beautiful body. She only needs the ability to pray”.

Gwynneth found comfort in the knowledge that Jesus carried illness and difference on the cross and that He therefore was able to understand. “Our children with their problems are being hated, rejected, despised, belittled, disparaged – as was Jesus.” She believed that even if it were true that the problems her children were experiencing could be “punishment”, Jesus had been punished so that we could have peace.

### 5.3.2 A journey from a theodic crisis or disorientation to a new theodic orientation

When we are confused and do not know how to connect our suffering to our belief in God, we are in theodic crisis (Brueggemann 1984; Louw 1983). Louw (1983:54) suggests four examples of theodic crisis:

- God wants to prevent evil, but cannot (then God is a God of love, but not almighty).
- God has the power to prevent evil, but does not want to (then God is almighty, but not a God of love).
- God has neither the power, nor the will to prevent evil (then God is neither almighty nor a God of love).
- God has the power to prevent evil, but He/She wills suffering (then God is the author of sin).

The report of the task force on severely handicapped children adopted at the 1985 General Assembly of the Presbyterian Church (USA) highlighted the irony that religious beliefs could become ambiguous in light of disability, as many parents said that religious beliefs only served to confuse them (Ikeler 1990:239). Adding to their dilemma was the fact that pastors and others would easily consider them as "wrongdoers" when they were not able to connect their suffering with their belief in God (Ikeler 1990:239). The effect of this interpretation of the Christian belief system was that families were alienated from the Christian community.

Brueggemann (1984) introduces a notion that I think reflects well on the remarks made by Ikeler (1990). Brueggemann (1984:11) suggests that Christian piety and spirituality are romantic and unreal in its positiveness: "As children of the Enlightenment, we have censored and selected around the voice of darkness and disorientation, seeking to go from strength to strength, from victory to victory. But such a way ... is a lie in terms of our experience". This selective (and romantic) tendency is reinforced by liturgical practice in the church, which makes use only of "positive and 'nice' psalms that support the polite hermeneutic of the church" (Brueggemann 1984:16) and to keep the psalms "within the confines of conventional spirituality" (Brueggemann 1984:168). I would argue that not only worship, but also Christianity in practice has become rather romantic: the important issue has become to do the "right" thing and not the struggle to make sense of an extremely confusing world. Apart from being driven to success, the liturgy in reformed churches, starting with a song praising God, followed by the law and repentance, can be experienced as if all good is being ascribed to God and all sin to us as "wrongdoers". "How can we ever feel good, if the good always belongs to God and we only own sin!" (Kotzé 2001).

Perhaps this "romantic" and "positive" view of Christianity makes sense in the absence of suffering and hardship. However, when suffering befalls us - when we are confronted with disability - we are hurled into theodic crisis and disorientation. The agony of this situation drives us to find a new orientation. Unfortunately, "the pastoral guidance which persons receive in their search for a new orientation frequently turns them back – as Job's friends hoped to do for Job – toward the standard orientation: bad deeds bring suffering; God imposes suffering as punishment for sins" (Ikeler 1990:240).

The dilemma of this kind of pastoral guidance appears to be justified in Scripture. Writers of the Old Testament "subscribed to the dictum that God rewards the obedient and punishes the sinful" (Ikeler 1990:240). This notion continues in the New Testament as the authors of the gospels report only one occasion - the story of the man who was blind from birth - where Jesus corrected his disciples' perception that suffering was the result of sinning. When the disciples asked Jesus: "Whose sin was it that caused him to be born blind? His own or his parents' sin?" Jesus answered: "His blindness has nothing to do with his sins or his parents' sins. He is blind so that God's power might be seen at work in him" (John 9:2-3).

Adding to the theodic crisis of families with differently abled children, are the ideas offered by prosperity theology proclaiming that "the atonement of Christ guarantees for all Christians divine healing for good health, the riches of this world if we follow certain principles, and a life of happiness without unnecessary sufferings" (Kim 1996:14). This view is sometimes called the "slot-machine religion .... You can have anything you want. You just name it and claim it; then it's yours" (Kim 1996:18). If your faith is not "real" enough, or you have any doubt, consequently you will not receive it. "If there is any failure [in this case, not being healed], it is your fault" (Kim 1996:18). However, Kim points out that although faith in Christ saves all sinners, faith healing does not always procure healing. He refers to a study that determined "only 5% - 10% of those who sought healing are helped from feeling better to complete healings" (Kim 1996:19).

The ideas propagated by prosperity theology, together with the perception that evil could befall the innocent "catapult the disabled into a stress-producing spiritual catch-22" (Ikeler 1990:240). Should the church appear to maintain that suffering was punishment imposed by God, or even the result of one's little faith or doubt, then many with differently abled children would interpret their child's disability as punishment by God and "turn their backs not merely on the church but also on God" (Ikeler 1990:240). To remain within the community of believers, they would be required to accept that they are sinners and would be expected to look upon God for mercy. But if they were convinced, like Job, that they were innocent – or not at least so guilty as to deserve the terrible "punishment" their child's disability constituted – they could not "thus confess and plead, if they [were] to keep their integrity – a choice between self-abasement and atheism!"

(Ikeler 1990:240). This was exactly the dilemma that most of the women in the group found themselves in (see paragraph 5.3.1).

If we declare or imply that sinning is the *only* source of suffering, if we take this as the "correct assessment of reality" (Ikeler 1990:240), "we hinder Job-like persons who are searching for an alternate theodic formula, a new theodic orientation" (Ikeler 1990:240).

Brueggemann (1984) suggests that the psalms invite us into a more honest facing of the darkness for even in the darkness, there is One to address, One who is in the darkness but is not simply part of the darkness. "Because this One has promised to be in the darkness with us, we find the darkness strangely transformed, not by the power of easy light, but by the power of relentless solidarity" (Brueggemann 1984:12). Louw (1983:55) also offers a new theodic orientation - that God is in our suffering. However, we are not to reverse this by saying suffering is in God. Debbie found such a new orientation when she said: "I can look back and see where God was present and how He helped me."

Ikeler (1990:242) quotes a psalm written by a young pastor, Nancy Blakply, as a prototype journey across theodic disorientation toward a new orientation:

O God, where are you?  
It is dark. I am tired.  
The day has been filled with so many frustrations; I wonder "Will it ever end?"  
I fight against the routine of caring for one so helpless, the odds stacked against her, never able to make it on her own.  
These mundane motions are a trap. I catch only fleeting glimpses of you shining through her.  
So I resist the tide that threatens to engulf me.  
I wanted only sweetness and light – not braces, feeding tubes, and constant watchfulness.  
O God, where are you?  
I feel so alone. I feel like giving up.  
Yet, she won't let me give up. You won't let me give up.  
You have already walked this road, and you walk it with me now.  
God, you are indeed wonder-ful. You won't give up.  
You won't let me go.  
Though I don't understand, you say, "Never mind, I am here."  
It is quiet now. The gentle raindrops on the roof lull me to sleep as you wash me and refresh me for tomorrow.  
Tomorrow. Perhaps tomorrow those glorious moments won't be so fleeting.

The poem describes a human's confrontation with God that involves neither confession nor forgiveness: a God/creature re-encounter made possible entirely by grace. Psalms, the Book of Job and comparable portions of Scriptures demonstrate that this mode of reunion is in no way less valid than other modes (Ikeler 1990:243).

### 5.3.3 A pilgrim on the journey

Although a pastor or pastoral therapist cannot get a person to produce an experience like that in pastor Blakly's psalm, the pastor or pastoral therapist can facilitate or co-construct with the person an alternative understanding of God, an alternative communication with God. This process of facilitation becomes possible only when the pastor frees him/herself from a confessional or fundamentalist approach (where a predetermined dogma functions almost as a doctor's prescription) and does not impose any predetermined dogma about God on people, but allows them to create their own way of constructing God, or relating to God in an honest way. "Pastors fulfil the priestly role when – in preaching, teaching, conversation, and by personal example – they show how lamentation and intercession, for self or for others, are authentically Christian actions" (Ikeler 1990:243). In his or her priestly role the pastor or pastoral therapist would not sanction the idea of God as a mighty despot, but would make room for a person's crying out in great pain against God as a legitimate form of prayer. The pastor or pastoral therapist is the one who accompanies the pilgrim on the journey from theodic darkness to theodic light, offering unwavering solidarity. In the group discussions I adopted the role of the pilgrim's companion. Although I was ready to give encouragement, I did not "designate the road. The pilgrim's companion follows the pilgrim, discreetly, from a distance" (Ikeler 1990:243).

I believe the metaphor Bosch (1979:66) uses of the chauffeur and the spare wheel is applicable to my commitment to the group as my preferred way of being as a pastoral therapist: Whereas the chauffeur is seen as driving the vehicle and steering it in the direction he or she has chosen, the spare wheel's role is complementary. In the same way Paul was to the Corinthians more spare wheel than chauffeur. "At no point does he offer – let alone demand – to take over the steering wheel. Throughout he does what a good spare wheel is supposed to do: he assures the Corinthians that he is there, at their disposal, should they need him .... He makes himself available" (Bosch 1979:66). However, the experiences that the group had of pastoral counselling indicated the opposite. They were adamant that the pastoral guidance they had received, was informed by a confessional discourse that kept them in a spiritual catch-22 situation (see paragraph 5.3.2).

In 2 Corinthians Paul uses the metaphor of an "aroma scattered by the incense-bearers". On the one hand, the fragrance rises up to God for his/her glory, but on the other hand, it also has a "decisive impact on all those who come in touch with it" (Bosch 1979:29). I would like to use this metaphor to describe the way in which we want to be "doing theology" (Ackermann 1996:33).

## **5.4 DOING THEOLOGY**

We, the participants of this study, no longer wish to suffer simply on the basis of a promise of a better life in the hereafter. For us faith means "responsibility for shaping one's own life in the trust of God, the God experienced in everyday life" (Isherwood & McEwan 1993:79). For us, what characterises our theology is the "awareness of our experiences ... in the doing of theology" (Isherwood & McEwan 1993:80).

### **5.4.1 A liberatory theology of disability**

In reaction to what we have experienced, and what has been said in the previous paragraphs, we argue for a liberatory theology of disability that includes "a deliberate recognition of the lived experience of persons with disability, a critical analysis of a social theory of disability and of certain aspects of the church's institutional practices and Christian theology, and the proclamation of emancipatory transformation" (Eiesland 1994:22). In practice that would mean that pastors would listen to and learn from the mothers of differently abled children, as well as other differently abled people. We believe that the church should take a lead in educating the congregation about disability. It would also mean that the church should reflect on their institutional practices and make amendments to their policies if necessary. Differently abled people should be incorporated into the life of the church by the creation of structures of participation so that they can equally participate in the faith community. The church should actively advocate for differently abled people, offer preventive care and create participatory practices in accordance to the wishes and preferences of differently abled people.

To initiate emancipatory transformation of the social-symbolic order, which includes the dominant practices and symbols of language, subjectivity and politics (Eiesland 1994:22), the notion of ableism should be deconstructed in theological reflection. Eiesland concentrates on the "'mixed blessing' of the body in the real, lived experience of people with disabilities and explicitly deconstructs any norms which are part of the unexpressed agenda of 'normal embodiment'" (Eiesland 1994:22). Incorporating differently abled people in the life of the church could be a first step towards deconstructing ableist ideas of the congregation, creating new images of wholeness as well as new discourses (Eiesland 1994:92). Working and living alongside the differently abled person, the congregation could learn how to create space for the specific needs of the differently abled person – for example to learn to give the person with a stutter the time he/she needs to complete his/her sentences; to wait patiently for the person with callipers to climb the stairs or to offer assistance for the person in the wheelchair.

Emancipatory transformation poses an enormous challenge to the "very loud, consistent, and powerful message" coming from our Western competitive individualism (Nouwen 1997:25). Nouwen (1997:25)



argues that this message "leads us to believe that we must prove our belovedness by how we look, by what we have, and by what we can accomplish. We become preoccupied with 'making it' in this life". This would mean that even if you can run faster and want to, you change your own pace and enjoy "walking with" rather than "running ahead".

After a distinguished teaching career Henry Nouwen, a Dutch Roman Catholic priest, went to share his life with people with mental disabilities as pastor of the l'Arche Daybreak Community in Toronto, Canada. There he cared for Adam for fourteen months. Under Adam's instruction, Nouwen learned to adjust to a new, slower rhythm of life and to speak with the language of the heart. "Sometimes when I was anxious, irritated, or frustrated about something that wasn't happening well enough or fast enough, Adam came to mind and seemed to call me back to the stillness at the eye of the cyclone. The tables were turning, Adam was becoming *my* teacher, taking *me* by the hand, walking with me in my confusion through the wilderness of *my* life" (Nouwen 1997:36).

#### **5.4.2 From autonomous individualism to "ubuntu"**

Another challenge for a liberatory theology of disability, in the context of a feminist theology of praxis, lies in challenging autonomous individualism and its affect on families with differently abled children. Autonomous individualism makes "an idol of the detached individual as self-sufficient, sovereign self .... The lonely self is cut off from community" (Oden 1995:28). How cut-off Suelene was from the community, became clear when she at one stage had to bring her two children with her to a group meeting. Her mother was ill and her husband on a business trip. She had nobody else she could ask to look after her children. I agree with Grenz (1995:98) that we must "shake ourselves loose of the radical individualism that characterizes the modern mind-set".

Within the group we found our spiritual stability through intimate experiences of faith together with others, through participating with others in our search for light and growth, through discussing and praying and often agonising with other Christians (Bosch 1979:67). What we needed from our communities of faith was "mutual care" which implied "actually living our redemption in Christ and executing our call to be Christ to one another and to others (Matthews 25:31-36), to bear one another's burdens (Galations 6:2) and endure one another's failings (Romans 15:1)" (De Jongh van Arkel 2000:15). According to Nouwen (1997:46), true care is mutual care; without that, care would become "little more than human maintenance".

The women in the group experienced that by participating in the other women's stories we were shaped and led to maturity, able to place our own stories in perspective. We experienced the spirit of "ubuntu".

Ubuntu is about the spirit of Africa - a person being a person because of other people. The essence of *ubuntu* is to know that a person, irrespective of age, colour and creed, is a human being and therefore needs to be respected. It is not about human rights but about human responsibility, respect and dignity, ethics and caring (Kotzé, Kotzé, Ramantzi, Lebeko, Mafojane, Masondo, Ntshokolsha & Tlhale).

However, we must not only shake ourselves loose from the radical individualism, we must also focus on spirituality (Grenz 1995:98-101). Theology must "take its lodging in the heart, for it is concerned with the transformation of not only the intellectual commitments, but also the character and the life of the believer (as well as of the faith community)" (Grenz 1995:101). Theology contributes to the resource that inspires action, for it seeks to "clarify the foundational belief structure which shapes our responses to the situations of life and which structure is reflected in the acts we choose to do" (Grenz 1995:101). Therefore, a feminist theology of praxis arises from the need to "reflect on Christian praxis in specific contexts for the sake of a better and more adequate praxis mediated through changed theories" (Ackermann 1996:42).

#### **5.4.3 Participation in life-changing theatre**

If the mending of God's creation lies at the heart of a feminist practical theological insistence on just, healing and liberating praxis, we cannot ignore the human relationships with God, others and the creation. As these relationships are reciprocal, it calls for accountability. Accountability "requires a hearing of and identifying with the voices from the outer circles and a resolve to live in such a way that the common good is advanced .... Accountability is ultimately tested in the reality of the well-being of all" (Ackermann 1996:45).

The social question – in this case the marginalisation of differently abled people and their families - therefore constitutes an important spiritual challenge for practical theology. Theological reflection should find its point of departure in the existing praxis, in its efforts towards improving concrete conditions in the society and the church. Brueggemann (1978:13) refers to a "prophetic ministry" which is "to nurture, nourish, and evoke a consciousness and perception alternative to the consciousness and perception of the dominant culture around us". Therefore, practical theology should be understood as "*a form of political theology*" (Heitink 1993:65).

Practical theological research is primarily understood as praxis-based research, with the intent of arriving at suggestions for further action. The aim of research is not just to increase knowledge, but also a change in the situation of the participants – contributing to competent and communicative action and in "doing theology" in an experience-oriented manner (Heitink 1993:172-177, Reinharz 1992).

In line with this way of thinking, we were compelled as the participants of this study to make our voices heard and to participate in the "theatre that is potentially life-changing" (Brueggemann 1993:24). We would like to apply this concept that Brueggemann uses to describe the prophetic challenge of preaching to describe our way of answering to what we perceived as our prophetic and political challenge. If we were not prepared to inform the church, doctors, therapists, nursing staff, teachers, and the community what we expect of them, we cannot blame them for acting in an inappropriate or insensitive manner – and we cannot expect change in our lived reality.

## **5.5 SHARING PIECES OF OUR LIVING IN MUDDY WATERS, FAR BEYOND THE MAIN STREAM**

In the group discussions the participants voiced the concerns and frustrations we experienced as mothers of differently abled children. It is like living in muddy "waters far beyond the main stream" (Perry & Gentle 1997:25). Certain practices and attitudes of the community add to the difficulties we have to face on a daily basis. We often have to face "narrow definitions of who we [and our children] are supposed to be" (Perry & Gentle 1997:25).

The postmodern paradigm reflects an acknowledgement that all claims of reality, including those by theologians, are "fully under negotiation" (Brueggemann 1993:17). We, the mothers with differently abled children, decided that we were no longer prepared to be trivialised outsiders, but that we wanted to participate in these negotiations for a changed social context. We believe that, through the telling of our stories, we can provide some of the "little pieces out of which people can put life together in fresh configurations" - and that over time, these pieces will be "stitched together into a sensible collage" (Brueggemann 1993:20-25).

We therefore decided on the following lines of action, offering our little pieces in the hope that the collage to be stitched will add to the mending of the creation:

1. We composed letters to the church and the faith community, doctors, nursing staff, therapists and teachers voicing our concerns and providing suggestions as to what we expect of them. We plan to send the letters to the editors of *Die Kerkbode*, *Die Netwerk*, *South African Medical Journal*, *South African Nursing Journal*, *PhysioForum*, *Teachers forum*, *You* and *Huisgenoot*.
2. We want to take part in the construction of new inclusive models of preaching, including the lived experiences of differently abled people and their families. As a contextual practical theology values God speaking through the marginalized, we believe that our voice needs to be heard. We feel that our voice

echoes the voice of God, calling for compassion, tolerance and justice. We therefore decided to request the pastors of the congregations that we belong to, to dedicate a sermon or sermons to raise the congregation's awareness for the needs and feelings of families with differently abled children. We wanted the letters we wrote (see following paragraphs) to be included in the text of the sermon.

3. We plan to organise a performance in collaboration with Miemie and Jakkie, a ventriloquist and a puppet, to carry out our message of awareness for the feelings and needs of differently abled people. We plan to take the performance to nursery schools and Sunday school classes.

In the following paragraphs I discuss the letters we used to voice our concerns regarding the faith community, professionals like doctors and therapists, and the school. I regard the information included in the letters too important to have them attached as appendices and I therefore include them in the text.

#### **5.5.1 Addressing the faith community**

I discussed the voice of the church in the lives of the participants in paragraph 5.2. In order to explain our letter to the faith community, I would like to briefly discuss our experiences with the broader community as well as with our family and friends.

Sometimes we have to suffer pain and humiliation due to insensitivity of other people. They force us into the muddy waters with their insensitivity and cruelty.

Cameron told the story of two boys at the nursery school who tied a rope around her son's neck. They stood one on either side of him and pulled the rope, trying to execute the boy because in their eyes he was "abnormal".

Debbie told about the time when she and her son were shopping. Her son, wearing callipers, was looking at some toys. When another child approached him, standing beside him to look at the toys, the child's mother called him away with a concerned look at the boy wearing callipers.

Suelene's best friend abandoned her, because her friend felt that she had to compete with Suelene's child for attention.

As a result of these incidents, we asked ourselves a few questions regarding the influence of cultural ideas and the role of the church in forming and shaping the values of the community:

We wondered what values in our community could have been at work, convincing those two little boys to put the rope around the neck of another boy and try to commit a despicable deed like that? In what way were those values imprinted in their imagination? What values have we as a society taught them that are mirroring back to us?

We wondered about the role of the church and particularly of preaching. Was the church not supposed to form and shape the values of the community? What were those two children witnessing in Sunday school and church? Had they ever heard of the love of Jesus especially for marginalised people? What was blinding them to really see what they were doing? Could it be the Western ideas of ableism (see paragraph 2.6)? Had we shown them the love of Jesus or had they experienced this kind of treatment that they had shown?

We were prepared to make concessions to accommodate our differently abled children, but we experienced pain when others were not as willing to do the same. We realised that there were "strangers" who had not been through the "school" we were going through. On the other hand, could it have been the voices of intolerance from the community that blinded "strangers" to see the pain that their ignorance and intolerance caused?

Sometimes we were angered by the things people would say to us. They said to the mother of a child born with spina bifida: "Don't worry, everything will be fine." Or to the mother of a child with cerebral palsy: "Don't worry, things will be all right, you will see."

We found that people interfered with matters that did not concern them. Suelene told the story of the time she had to go to a store. As she forgot the perambulator at home, she had to carry both her children. A woman came to her and told her to put down the older boy, as "he was old enough to walk". Suelene could only turn around, stare at the woman in disbelief, told her that the boy could not walk, and went home – empty handed. Another time she was changing her son's diaper in the restroom of a shopping centre. As there were no facilities provided, she had to use the surface between the basins. She made sure there was nobody in the restroom. As she was busy changing the diaper, a woman entered. When she saw what Suelene was doing, she came to her, saying: "Siss, is this the place to do that?" "Look how big he is! Why is he not potty-trained?"

The attitudes of friends and family were a great source of pain and frustration to the mothers of differently abled children. During group discussions, we talked about how painful comments from friends and family could be. We were tired of keeping on saying and doing the same things over and over. Other people did not understand and said things like: "All that child needs is a good hiding! If it were my child, it would have been another story!" Or, "Give that child to me for a day/week/three weeks and you will have a different child back." We were tired of explaining our actions to other people.

Suelene experienced the lack of support and interest from her in-laws as a source of pain and frustration.

For Cameron, isolation was trying its best to come between her and her friends and family. She sensed that her friends and family were uncomfortable when she visited them; she felt unwelcome and stopped visiting them. Rina felt isolated, as her mother was not prepared to look after her son when he was a toddler.

Debbie's mother offered her a cup of tea or a couple of verses from the Bible as solution to all her problems.

Sometimes our families caused us pain, as they did not take our concerns seriously. They sometimes thought they knew better.

In order to make our voices heard we composed a letter to the church and the faith community, drawing on our own experiences. We included some ideas offered by Buford (2000:347-349) and Ikeler (1990:241-242).

*Dear faith community*

*We are a group of mothers with differently abled children. Some people call them "disabled"; others refer to them as "having disorders". We concentrate on the things they can do, rather than the things they cannot do. Therefore we prefer to think of them as differently abled.*

*During a series of group discussions, we shared our stories of mothering our differently abled children. Although we did not have the same experiences, we discovered similarities in all our stories. It is our experience that most of the professionals that we have to deal with do not take their responsibility seriously to inquire before displaying their "expert" knowledge. We therefore realised that we have to make our voices*

*heard. We have to inform doctors, therapists, nursing staff, teachers, the church and the public what we expect of them, in order to stop them acting in an inappropriate or insensitive manner.*

*We would like to share some of our experiences as mothers of differently abled children. Although we do not try to claim that we have covered the whole spectrum of experiences, we identified a few areas of concern. Perhaps when you read this, it will sensitise you to the needs and feelings of differently abled people and their families.*

### ***The faith community***

*We are concerned about the intolerance and insensitivity we experience from the community. We would like to share the following information with our faith community:*

*We would like to thank all who support us. To the "strangers", as well as our friends and family who understand our problems and try to make things better for us, we want to say thank you. You sustain us and help us through times when we are overwhelmed by the pain and sorrow of our lives.*

*Unfortunately, there are quite a number of people who are not sensitive to our feelings or our needs. We want to believe that the insensitivity that both our children and we are experiencing stems in most cases from ignorance rather than from cruel intentions. In an effort to make our voices heard, we would like to bring the following ideas to your attention. When you next encounter a person who is differently abled, please keep the following ideas in mind:*

*Please do not try to make us feel better with empty clichés like, "Do not worry, things will be better soon." We know things will not be better soon. What we sometimes need is a shoulder to cry on. Sometimes a break would be welcome. So, next time, before offering a cliché, offer some of your time so that we can have a break.*

*We would prefer other people not to question or criticise us. We are trying in the only way we know how to do our best for our children. If this does not fit your way of thinking, we want you to stop for a moment and give it a thought that we have to cope with much more issues than you have to. Perhaps we have already tried the method you are suggesting. With your "normal" children it could have worked, but we have to try out alternatives you do not even have to consider. We ask to be given the benefit of the doubt before you start to criticise. There could be issues involved that you do not understand.*

*If you have wonderful, talented children and you are aware of our struggles with our children, we ask for a more sensitive approach. We are already experiencing feelings of guilt and inadequacy; we do not need our faces to be rubbed in the successes of your children.*

*We are concerned about the intolerance of the community to accommodate our differently abled children. We wonder about what other children are taught at home and what examples our society sets. We cannot help but wonder where two nursery school boys got the idea to try and execute a boy who is different from them. They believed he should be killed because he was in their opinion "abnormal". We are curious to know how you would have reacted had your child been involved in an incident like that.*

*Both our children and we have numerous tales to tell of incidents like the above-mentioned. Once a mother called her child when he was talking to another little boy in a toyshop. The reason? The other little boy was wearing callipers. Disability is not contagious. You do not have to be scared of them.*

*To the marketing world we want to say that we believe that parents of differently abled children have become part of a moneymaking racket. Marketers use our commitment to help our children, to sell their expensive educational and/or other programmes and/or equipment to us. We are not informed of the cheaper alternatives.*

*To our friends and family we want to say that we sometimes sense intolerance towards our children. We do not expect you to love them the way we do. We also acknowledge that you are "strangers" who have not been through the "school" we went through. However, we will appreciate a little more compassion and understanding. We feel isolated when we do not feel welcome in your homes with our differently abled children.*

*We ask of you to support us in our daily struggles. Please do not abandon us - we have to put our children first.*

*We realise that the society we live in expects of individuals to carry their own burdens without outside help. Nevertheless, we know that we cannot cope on our own without the support of those close to us.*

*Living in a dominantly patriarchal society, we, the mothers of differently abled children, have no choice but to accept the role of the "mothering person" in our families, even though all of us do not feel equipped for the "job". To add to our burdens, we sometimes feel trapped in the middle of the battles between our*



children and their fathers. Among all the issues we have to cope with, we are forced into the role of "referee" between our differently abled children, their siblings and their fathers.

### **Suggestions for ministering to differently abled people and their families**

We would also like to share a few ideas with the pastors and church authorities:

As mothers of differently abled children, we believe that there is much to be done within the church to offer families with differently abled children a place of recovery and restoration. For this to happen, we believe that congregations and ministers have to examine their assumptions about chronic illness and so-called "disability".

To assist in the examining of assumptions, we have prepared a few suggestions that might prove useful. We urge you to listen to your own feelings while reading these suggestions. We realise the competitiveness of the world we all live in, but as mothers of differently abled children, mothers with limited energy, resources and often fragile egos, we request you to listen to our plea. We realise that we are perhaps expecting too much. We know the church also has an obligation towards the homeless and unemployed, and that an enormous amount of energy is needed for the caring of these people. However, we hope that our message gets through.

We appreciate efforts to make church buildings and other places of worship accessible by putting up ramps and hand railings. However, we believe that accessibility stretches further than buildings.

Our suggestions focus on two areas of ministering to families with differently abled children.

Firstly, we believe that you will be able to access valuable information from mothers of differently abled children – information that could benefit the congregation's understanding of being differently abled.

- Listen to mothers of differently abled children. Do not make assumptions about their lives or the lives of their children. If you have emotional baggage preventing you from entering their worlds, get supervision and/or try therapy to deal with the baggage.
- Try not to be scared of, or to be associated with differently abled people. You may pick up skills from a mother or family member of a differently abled child that might prove helpful in future.
- Avoid stereotypical remarks such as "Don't worry, things will be better soon", or "God has given you this child to teach you patience", or "Don't worry, one day in heaven your crown will be bigger and brighter!"

- *Be aware that your attitudes towards differently abled people might speak louder than your words. Be careful not to be patronising.*
- *Inform yourself about the resources and support groups already existing in your community.*
- *Inform your congregation about chronic illness in general and about specific illnesses. Provide seminars, literature and information about support groups.*
- *Offer brainstorming sessions or awareness campaigns with the aim of clearing up misconceptions regarding being differently abled. Differently abled people could be invited to lead these sessions.*
- *Be sensitive to the use of words like “crazy”, “abnormal”, etc – especially from the pulpit. There might be people in the congregation who could be hurt by inconsiderate references to people being differently abled.*
- *Try to avoid telling mothers of differently abled children to “trust God” or to “put God first”. Help them to develop practices that will enable them to be more aware of God and the development of their faith. Ask these mothers to help the congregation by sharing what they have learned from living their lives on the margins of society.*
- *Be aware not to equate illness or being differently abled with sin or God’s judgement. Many mothers of differently abled children already have low self-esteem and blame themselves for the conditions of their children.*
- *Although we want to believe that if one has enough faith anything could be possible, we have lived long enough to realise that some things in life will not change. Instead of applying faith to change our situations, we require faith nourishment to sustain us in our daily struggle against despair and depression.*

*Secondly, we believe that we need your support. We therefore urge you to be aware of possible crisis, to try to meet our needs and to show your support in meaningful ways.*

- *In times of crises, please offer concrete help such as meals for the family; taking care of the siblings of the differently abled child when the mother has to take her/him to the hospital/therapy; transportation, visits and prayer. The best is to ask how you could be of assistance – do not rely on assumptions about how you can offer help.*
- *Keep in mind to minister to the whole family – no one suffers in isolation. Family systems with one member being differently abled are exposed to constant change. Not all marriages are able to withstand the strain brought on by the challenges of having a differently abled child.*
- *Families with differently abled children run the risk of becoming isolated. By linking them with community organisations you can help them overcoming isolation.*

- *Not all relatives and friends are necessarily comfortable having a differently abled child in the family. Perhaps the church can play a role in overcoming isolation and stigmatisation connected to being differently abled. The hush surrounding the issue could be cleared by means of a special service to which the disabled family, their relatives and friends could be invited. The service could be followed by a meal and a "gathering of the clan", aimed at opening up communication between the family and their close relatives and friends. Discuss isolation and stigmatisation with relatives and friends.*
- *Offer to pray with and to help find consistent, ongoing support for families with differently abled children. Consider the role that prayer partners, friends, spiritual directors, pastoral counsellors, or ongoing support groups could play in this respect.*
- *Be willing to offer pastoral care rituals to families with differently abled children.*

*We sincerely hope that in reading this you have gained some insight into the lives and experiences of differently abled people and their families. We would feel that we have accomplished something positive if even one person, in whatever way, would be able to change his/her attitude towards differently abled people after reading this. Thank you for listening to us.*

*Yours sincerely*

*A group of mothers with differently abled children*

### **5.5.2 Addressing doctors, nursing staff and therapists**

The attitudes of doctors and therapists were of enormous concern to the mothers of differently abled children. Our conversations in the group focused extensively on our relationship with doctors and therapists. We were all abhorred when Debbie told us about the therapist who said, as she was handing her baby back to Debbie, "What would become of this child is now in your hands." Although we realised that the therapist's intentions were good, we all could relate to this implied sense of responsibility recruiting Debbie to turn into the perfect "caretaker", the one that would ultimately be responsible "what would become of this child".

We are sometimes confused and frustrated when we have to deal with medical professionals. When we are concerned about our children and take them to the doctor – granted, perhaps sometimes too soon or even unnecessarily - they accuse us of being over-protective or even "neurotic". When we do not take our children to the doctor, they accuse us of being negligent. When the doctor makes a mistake, like a wrong diagnosis, it is passed off as "human error". When we make a mistake, we are "bad" mothers.

Most of us experienced that some professionals (therapists, doctors or nursing staff) do not listen to and consult with us as mothers. We sometimes experience lack of compassion from them. We believe that "even a little sign of understanding or compassion would help a lot".

However, sooner or later we all have to face the reality where no "one-size-fits-all" solution exists, and that the advice that we receive from professionals has to be tailor-made to fit our own unique circumstances. What we request from the professionals we have to deal with, is to acknowledge our hard-earned local knowledge about our children, our own feelings and our own unique circumstances. Sometimes we are confused by all the jargon we are bombarded with. Yet we realise that these professional do not have all the answers.

We encourage doctors, nursing staff and therapists to take cognisance of the following:

*Dear doctors, nursing staff and therapists*

*We are a group of mothers with differently abled children. Some people call them "disabled"; others refer to them as "having disorders". We concentrate on the things they can do, rather than the things they cannot do. Therefore we prefer to think of them as differently abled.*

*During a series of group discussions, we shared our stories of mothering our differently abled children. Although we did not have the same experiences, we discovered similarities in all our stories. It is our experience that most of the professionals that we have to deal with do not take their responsibility seriously to inquire before displaying their "expert" knowledge. We therefore realised that we have to make our voices heard. We have to inform doctors, therapists, nursing staff, teachers, the church and the public what we expect of them, in order to stop them acting in an inappropriate or insensitive manner.*

*We would like to share some of our experiences as mothers of differently abled children. Although we do not try to claim that we have covered the whole spectrum of experiences, we identified a few areas of concern. Perhaps when you read this, it will sensitise you to the needs and feelings of differently abled people and their families.*

*We would like to thank the doctors and therapists for the help they offer us when we really do not know which way to turn to with our children. Some of you really help us and we sincerely appreciate the advice*

*you have to offer. Especially your sensitivity and kindness remain with us and sustain us on our journeys. It soothes some of the sorrow and pain we have to face daily.*

*However, some of you are sometimes insensitive to our feelings, our dreams and concerns. When dealing with mothers of differently abled children, would you please consider the following ideas?*

*We experience that some doctors rarely listen to us as women or to us as mothers. Almost each of us has a tale to tell of a doctor who did not listen to us regarding our children. Complaints about our emotional state are often discarded as "hormonal imbalances".*

*We came up with the following understanding of the above-mentioned attitudes. We accept that each professional may have his/her own preferred field of expertise and may use this as the only meaning system. Yet we feel that listening to our needs and concerns sometimes do not form part of that meaning system.*

*Once a diagnosis is made and medication is prescribed, the doctor loses interest. It is often difficult to get hold of the doctor should we want to discuss the prescribed dosage or unexpected (unexplained?) side-effects. Not all of us deserve to be thought of as "neurotic" or "over involved mothers". We sometimes get confused by conflicting information among yourselves. However, we believe that we deserve the attention of the doctor should we need to discuss our concerns regarding the prescribed dosage or side-effects.*

*We request professionals to honour our privacy and not fax confidential results of tests to our offices where everybody can read and comment on it.*

*We request doctors to inform us of the integrity of suppliers of the equipment our children need. We believe that we have the right not to be exploited by these people, just because we are at their mercy. We expect of doctors and therapists (if they have the information) not to refer us to those suppliers who charge us R5000 for a product we can buy elsewhere for R399. We believe it is part of their professional service to us to make sure of the credentials of the suppliers they refer us to.*

*It would be helpful if doctors and therapists were more appreciative of our own efforts and less critical of the way we do things. We ask of you to be more sensitive and appreciative of our own inputs and efforts.*

*We have to face the reality where a "one-size-fits-all" solution does not exist and where the advice we receive has to be tailor-made to fit our own unique circumstances. What we ask from doctors, therapists and nursing staff we have to deal with, is to acknowledge our local knowledge about our children, our own feelings and our own unique circumstances. Please show a little more compassion and understanding.*

*We believe that we are entitled to respect for the knowledge we have gathered in our daily struggles with our children. We do not claim to be experts on all disabilities, but we do read and learn about the conditions of our children. We would like you to acknowledge our knowledge. Please pay attention to our opinions. Sometimes we could save money and valuable time if attention were paid to our opinions.*

*It helps us if we are understood and we do not feel so isolated when somebody understands what we are talking about. Sometimes we are amazed at the lack of compassion we experience in our contact with you.*

*Once a therapist told a mother whose baby was suffering from cerebral palsy: "What will become of this child is in your hands."*

*May we ask doctors and therapists to be sensitive to our notion of being overwhelmed by feelings of guilt for anything that concerns our children, and to help us to stand up against this notion? Sometimes it will be helpful when professionals protect us against ourselves and assure us of our good intentions and care for our children. In cases where this happened, mothers responded very positively.*

*It seems to us that professionals may not be as interested in new developments in the field of research. We do not expect of you to be as enthusiastic as we are about possible solutions, but please, would you be able to acknowledge it or refer us to someone interested in the relevant research? Our hope is to be relieved of our difficulties.*

*We feel threatened by the high premium put on primary health care. We sometimes do not experience our children and their problems to be considered a priority for professionals or to the community. If patients who are in need of kidney transplants are considered a burden, how much more our differently abled children?*

*We sincerely hope that by reading this, you have gained some insight into the lives and experiences of differently abled people and their families. We believe that even if we could change the attitude of only one person, even in a very small way, we have accomplished what we wanted to. Thank you for listening to us.*

*Yours sincerely*

*A group of mothers with differently abled children*

### **5.5.3 Addressing teachers and the education system**

Another area that concerns us is the school system and the attitude of teachers towards our children, as well as to us as mothers.

We believe that people do not value our children for what they really are – we suspect them of being blinded by the cultural ideas of success and IQ, of ableism. During their school years they are easily rejected because of their unique abilities. They are not understood and appreciated by the school system. They are constantly confronted with the things they cannot do while the things they are good at “count for nothing”. They are constantly confronted with failure, only because they are “not doing things according to the way someone else has decided that that is the way things should be done”.

Their exposure to all sorts of medication and therapies to “fix” them attributes to a process of further breaking down their self-confidence. It is ironic that the teachers – and we have to admit that as mothers we sometimes do the same thing – are trying to “fix” them. We are doing this without knowing or even trying to understand what they are thinking.

In our letter of concern we would like to draw the attention of everybody concerned in the education of children to the following.

*Dear teachers*

*We are a group of mothers with differently abled children. Some people call them “disabled”, others refer to them as “having disorders”. We concentrate on the things they can do, rather than the things they cannot do. Therefore we prefer to think of them as differently abled.*

*During a series of group discussions, we shared our stories of mothering our differently abled children. Although we did not have the same experiences, we discovered similarities in all our stories. It is our experience that most of the professionals that we have to deal with do not take their responsibility seriously to inquire before displaying their “expert” knowledge. We therefore realised that we have to make our voices*

heard. We have to inform doctors, therapists, nursing staff, teachers, the church and the public what we expect of them, in order to stop them from acting in an inappropriate or insensitive manner.

We would like to share some of our experiences as mothers of differently abled children. Although we do not try to claim that we have covered the whole spectrum of experiences, we identified a few areas of concern. Perhaps when you read this, it will sensitise you to the needs and feelings of differently abled people and their families.

We would like to thank the thousands of teachers who really try hard to understand the difficulties attempting to overpower our children and who are supportive of our children and us as their mothers.

However, we have to cope on a daily basis with issues that concern our children and therefore ourselves. Our concerns are summarised as follows:

Sometimes school systems/policies concentrate on trivial matters in the face of problems that seem to us as much more important, for example:

- Our children have to cope with a lot of stress at school. At home we are working hard to build our children's self-confidence in the face of so many forms of rejection they experience at school. We ask you to keep in mind that one incident where the child feels humiliated in front of his/her classmates can undo much of our hard work. When their hair is a little untidy, or a bit longer than the school rules prescribe, may we ask for a little more tolerance, before humiliating her/him in front of the other children? We do not expect of you to ignore the school rules but what we ask for is a more sensitive approach.
- We realise that it is not always easy for teachers to cope with the demands of the special needs of our children in an overcrowded classroom. However, tolerance goes a long way to create an atmosphere of acceptance towards each other in the classroom.
- We experience the school system as rigid, and not yet ready for the special needs of our children. In an effort to suggest some alternatives, we pose the following questions:
  - Could a child whose handwriting is not up to "standard" be allowed to use a computer instead?
  - Why do children have to write either in print or cursively?
  - When a child prefers to use a pencil and not a pen, why is this not acceptable?
  - Sometimes a child can feel so battered as a result of his difficulty with spelling that he/she can lose his/her motivation completely. Is it possible to be more lenient towards his/her inability to spell and concentrate on what he/she is able to do?



*The system of assessment and examination does not always allow for our children's special needs. This argument stems from the question of what is being tested? Can this system be made more flexible?*

*We wonder to what extent the age-old attitude of "there are no problem children, only problem parents" contributes to the problems we are experiencing.*

*Although we are grateful for the facilities offered by schools like New Hope, we regard the help from government as inadequate. We are responsible for the costs of all the therapies we have to engage in for the benefit of our children. Medical aid funds do not always contribute to these costs.*

*Regarding authorities and policy making, we are concerned about the rumours that schools for children with different abilities, like New Hope, are going to be phased out. We are concerned about the following issues:*

- The fact that we are not informed, and therefore do not understand the process taking place.*
- Is the mainstream community ready and prepared to take responsibility for our children? We believe that they need to be sensitised towards the special needs of our children. We wonder about the training of teachers – will the special needs of our children form part of the future curriculum of all teachers?*
- All our children had bad experiences with bullying. Do the authorities intend strategies to protect our children?*
- Should schools for children with different abilities be phased out, how will mainstream schools be funded to accommodate the special needs of our children?*
- We believe that we have the right to be included in the decision-making process, and the formulation of new policies that affect our children, as well as being given options in this regard.*

*We sincerely hope that by reading this you have gained some insight into the lives and experiences of differently abled people and their families. We believe that even if we could change the attitude of only one person, even in a very small way, we have accomplished what we wanted to. Thank you for listening to us.*

*Yours sincerely*

*A group of mothers with differently abled children*

## **5.6 INVOLVING THE CONGREGATION**

At this point two pastors of the Dutch Reformed Church are willing to dedicate a sermon to the cause of sensitising the congregation to the needs and feelings of families with differently abled children.

One of the pastors attended a group session that was arranged for this purpose. He used the information he obtained while listening to the mothers to prepare his sermon. The sermon will be delivered early next year.

The other pastor, who offered to dedicate a sermon to this cause, studied the letters discussed in the above paragraphs, as well as a list of incidents from our real life experiences that we prepared for him for this purpose. He also interviewed me on the group discussions and our ideas about the sermon.

He prepared his sermon on Mark 10: 35-45. The main theme of the sermon was that the cup that Jesus had to drink was that of being of service to others. A mother of a child with cerebral palsy (who is a well-known member of the congregation) delivered a testimony, and thanked her friends and family for their support, for she would not have been able to cope without their love and support. She also asked the congregation not to be scared of disabled people, as they are "actually quite normal", and offered some ideas of how to approach a differently abled person. The congregation was very touched by the sermon and testimony. Feedback from the congregation indicated that the sermon served the purpose of sensitising people to the experiences of differently abled people and their families.

The pastor also prepared a paper for discussion to be used in small groups during the following week. The small groups involve about ninety per cent of the congregation. The discussion paper made use of an excerpt from the book *Raaiselkind* by Annelie Botes, illustrating some of the pain that parents of differently abled children has to live with. A few questions were provided to guide the discussions (see appendix E). I accepted invitations to some of the small groups to inform them on the research project.

## **5.7 MIEMIE THE VENTRILOQUIST**

The women in the group have decided to continue to meet on an informal basis. We are convinced of our prophetic responsibility towards society, and the involvement of Miemie and Jakkie is one of the projects we are keen to see through.

## 5.8 CONCLUSION

What we attempted to do by sharing our stories was to "*fund* – to provide the pieces, materials, and resources from which a new world can be imagined" (Brueggemann 1993:20). We do hope that by "funding", by making available those pieces, we have contributed to a process of transformation – a process towards a transformed consciousness. We hope that the reader would "go away changed, perhaps made whole, perhaps savaged" (Brueggemann 1993:24). Our hope is that over time, those pieces will be "stitched together into a sensible collage, stitched together, all of us in concert, but each of us idiosyncratically, stitched together in a new whole – all things new!" (Brueggemann 1993:25).

## **CHAPTER 6: REFLECTIONS ON THE RESEARCH JOURNEY**

### **6.1 INTRODUCTION**

In this final chapter, I adopt a reflective position by looking back on the research journey as a whole, on the research curiosity and the questions addressed by the research. New questions are posed and I reflect on some of the possible implications and suggestions for the therapeutic discourse and for practical theology and pastoral therapy.

This research argues that we understand and live our lives through stories. Narrative therapy takes up the "story" metaphor to question those "taken-for-granted" realities and practices that shape – and sometimes restrict – our lives (Nelson 2000:13). As therapist and researcher I found myself immersed in these cultural stories – and so did the participants of this study. By questioning these taken-for-granted knowledges and deconstructing them, I attempted to make available other stories that could offer different possibilities for shaping our lives. We could become aware of more possibilities available to us. We could exercise some choices. That enabled us to claim a form of agency in which we could move within and between discourses (Davies & Harré 1990:46).

Our stories are constructed through the self and society. This notion suggests that these stories could also be deconstructed. The process of deconstruction implies the exploration of neglected and un-storied (White & Epston 1990) versions of our life-stories. By cultivating these neglected and un-storied events (Freedman & Combs 1996), new and preferred ways of being are constantly being developed. In the process, preferred outcomes become a possibility. Since our stories are constructed through the self and society, there are multiple realities and therefore multiple voices and multiple stories. As a result of prevailing dominant discourses in our society, of societal stories dominating the self-story, the mothers in the group were confined to thin descriptions about themselves and their stories.

This chapter reflects on the practices used to achieve the outcome of making the voices of mothers with differently abled children heard and to discover alternative, preferred mothering practices.

### **6.2 THE CHALLENGES OF THE STUDY**

Many feminists have argued that "finding one's voice" is a crucial process in their research and writing. While writing this report, I experimented with different ways of writing and tried out alternative voices. I wanted to tell the stories the women shared in the group in a way that their voices were not marginalised by

my own voice as researcher or by academic voices. I did not want to speak *for* the women in the group, but speak *out* for them (Reinharz 1992:16).

The basic aims posed at the outset of this study (chapter one) focused on an exploration of the influence of social constructed discourses regarding motherhood and ableism on mothers of differently abled children, and how these discourses have affected and informed them. It also focused on the exploration of the parent/professional relationship and the co-construction of alternative stories, deconstruction of dominant discourses and the re-telling of their preferred mothering stories. Chapter two provided ideas on the social construction of motherhood and ableism in society. In chapter three I gave a brief outline of the research journey, and introduced the participants.

The descriptions of the group meetings by means of the reflective letters (chapter four) illustrated how the narrative process was used to externalise the discourses informing the participants, the effect on their mothering practices, and the thin descriptions they have formed of themselves as mothers. The group setting provided multi-opportunities to allow the women to become visible and to talk themselves into existence (Davies 1993:21). In chapter five I focused on pastoral care for families with differently abled children. I also touched on “doing theology”, describing the actions the group initiated in order to bring about a change in the situation of all differently abled people and their families.

### **6.3 REFLECTIONS: INSIDERNESS, LETTERS, NARRATIVE THERAPY AND GROUP WORK**

In the following section I reflect on the research process.

#### **6.3.1 Insiderness**

Like feminist researchers frequently do, I began my writing with the personal connection I had to the research topic. I found that my troubling experience became a “need to know” - I drew on the “epistemology of insiderness” (Reinharz 1992:260). Being an insider of the experience of being the mother of a differently abled child, enabled me to relate to the stories the mothers told in a way that no outsider could. I was moved by their stories, and the stories I heard changed my own story.

I wanted to share this with the group, and wrote in one letter:

*I want to thank you from the bottom of my heart for your participation in this project. You enriched my life so much. I would have been a very poor person had I not been granted the opportunity to know you, and to share in your stories. I once read that by telling our stories we write ourselves into*

existence. Through our group discussions, I experienced that I talked my story and myself into existence. By being able to witness your stories and to share in your pain and sorrow, moreover by being able to witness and share in your stories of hope and the humour you wrapped your stories in, my story changed.

Firstly, my story became real. There has always been a side to this experience that tried to convince me that my story as Henk's mother was not "real", - that being his mother could not have been so difficult, "it was all in my mind", I was the one "who could not deal with it". The cultural voices we often spoke about even tried to convince me that I was "selfish" and "self-centred" to be so concerned about myself and my own feelings in the face of the difficulties Henk had to deal with. Those ideas occupied a huge space in my mind, blurring my reflections on being a mother and of developing my preferred identity as the mother of a child with different abilities.

Secondly, my story fell into perspective once I heard your stories and knew it was not my imagination, but "legitimate" feelings and experiences. I was not the only one who had been angered by the insensitivity of therapists. I was not "at fault" when I took exception at the well-intended, but totally inappropriate advice of my family and friends. I was not "stupid" because I became confused by the conflicting opinions offered to me by therapists and doctors, I was not "a wimp" because I did not always have the courage or energy to stand up against the "useless" ideas or advice of therapists, or against insensitive remarks of other people.

By telling your stories, you gave voice to my experiences. By listening to your stories, my "emotional marathon" started to make more sense. It was no longer a mere senseless putting one foot in front of the other, just to keep going. It became part of the "bigger picture". By telling your stories, you taught me to recognise the voices of the culture I am living in and to interrogate them. I no longer take them for granted, or accept them without questioning.

Thirdly, it was through sharing in your stories that I found the courage to resist the role forced upon me as Henk's mother and everything that came with it. It is particularly the "ultimate responsibility" and the "blaming" part that I would like to stand up to. Listening to your stories and sharing in your experiences, was to me "a step towards empowerment".

However, this "insiderness" sometimes blurred my perspective from a therapeutic point of view, especially in the beginning of the research journey. I found it difficult to engage in externalising conversations. I was

caught up in the same cultural voices as the rest of the group - I have been living with these voices for the past fifteen years!

The tape-recordings of the sessions were of great assistance. During the sessions the tape recorder took over the part of the "co-searcher" (Dixon 1999:45) and I became part of the group. Afterwards, while I listened to the recordings, I claimed back the role of "co-searcher". I was able to externalise the issues that were discussed and to recognise the cultural voices that also contaminated me.

### **6.3.2 Letters**

The reflective letters I composed after each group meeting gave me the opportunity to facilitate the process of co-authoring alternative stories, using the medium of written language to continue and enrich the conversations (Epston 1994:33). It gave me the opportunity to reflect on what happened during the sessions. Using externalising language, I created possibilities for the participants to intervene and make changes, rewrite their stories so that the issues they discussed had less influence on them. It also gave them the opportunity to internalise their own preferred stories (Epston 1994:32).

### **6.3.3 Moment of insertion**

I was profoundly affected - sometimes overwhelmed - by the sadness of the stories I heard. The story that Cameron told of the two boys trying to kill her son moved me to tears. I was not sure whether it was anger or sadness that affected me most: Anger at the insensitivity of a community and sadness for the boy who had to make his journey through life with the "knowledge" that he was not worthy of living because of his "differentness". This story was a "moment of insertion" (Cochrane, De Gruchy & Peterson 1991:17) and much of the action that the group decided to take originated in that story.

Another time when I was overwhelmed by emotion was the Sunday morning following a session where Debbie described her spiritual journey. In coming to terms with her son's sufferings, she was struggling in particular with the belief that God gave his children only "good" things. Her story of tears and struggles she suffered due to Christian beliefs like these, was still fresh in my mind when the pastor repeated that same sentence in his sermon that Sunday morning in church. I could not hold back my tears. I was upset by the idea that the pastor did not have a clue of how his words affected some individuals in his congregation - of the way the words he used constituted the lives of the members of the congregation.

#### **6.3.4 Witnessing**

Initially my commitment to the study was for the participants to share in the deconstruction of dominant discourses of motherhood and ableism; for each mother to discover her preferred identity as a mother of a differently abled child and to develop her own preferred mothering practices. From the first session it was evident that the participants needed witnesses to their stories. As I was determined to follow an approach of power sharing and narrative free-ranging conversations where the participants would help set the agenda, the emphasis of the study shifted more towards listening to their stories and creating a platform where they could vent their feelings and make their voices heard – to create a space where they could be safe. I therefore refrained from introducing topics for discussion. They just started talking and kept on talking way past the hour and a half we had planned for the sessions. The participants had never before had the opportunity to tell stories that had been bottled up for so long (see paragraph 4.2).

It was not easy to give up my own research agenda. I had to remind myself of the influence of capitalism in the sense that in everything we undertake, we think in categories of success, of yield and dividends (Bosch 1979:31). The result is that we “feel terribly embarrassed when we cannot report tangible results”. I recognised my “fear for embarrassment” that the outcome of the research would fail to produce tangible results if I did not come up with answers to all the questions I posed at the onset of the research.

I was encouraged by the observation made by Wright, Watson and Bell (1996:161) that families find therapist’s invitations to engage in meaningful conversations about the impact of illness in their lives as one of the most useful interventions in assisting families to move beyond and overcoming problems. “The capacity of clinicians to be ‘witnesses’ to the stories of suffering of patients and families is central to providing care; it is frequently the genesis of healing, if not curing” (Wright, Watson & Bell 1996:161).

In this sense I believed that the research contributed to ethical ways of research.

While writing this report, it came to my mind that perhaps the title of the research should rather have been “Witnessing the stories of mothers with differently abled children”.

#### **6.3.5 Preferred ways of mothering**

Even though I did not introduce topics for discussion, through the sharing in the stories of other mothers in more or less the same situation, and through the reflecting letters, some of the participants arrived at their own alternative, preferred ways of mothering. Rina decided that she was no longer prepared to allow guilt to rule her life. She invited other voices into her life, thickening her description of her identity as a mother.



She was able to situate the problems concerning her eldest son into the context of her mothering practices concerning her other children as well. She said: "Never before have I talked to someone else who shared my feelings and concerns. It was after I shared in the stories of other mothers, that I realised my son is what he is – not because I made him so." Finally she found her voice: "I am not a bad mother."

### **6.3.6 Group process**

When reflecting on the research journey, all the participants voiced their appreciation for the group process and the unwavering solidarity we experienced in the group. Moira said: "The group sessions allowed me the opportunity to spend time on myself, away from the demands of husband and children. It was an outing. I could relax and talk about myself and the things that are important to me, about my feelings." She was prepared to sacrifice her much-needed sleep after a nightshift at the hospital, to take part in the group sessions. Debbie appreciated the friendships she formed in the group. And through sharing in others' mothers' stories, her own story "fell into perspective": "The troubles of some of us seemed smaller, others bigger. What counts, is how we react, what we make of our experiences." Rina could find a new perspective through the knowledge that she was not the only one to experience the feelings she thought she alone was burdened with – most of the mothers in the group expressed similar experiences.

### **6.3.7 Participatory research**

Accepting the ethical stance of a narrative approach, I wanted to privilege Henk's right to choose whether and how he wanted me to talk about him in his absence. I therefore asked his permission to talk about him in the group discussions. I assumed that the participants would hold the same opinion. However, some of the participants were simply too tired to contemplate this possibility, to negotiate their participation in this project with their children. By not "taking on another issue" they thought they were protecting their children from yet another source of stress (see paragraph 3.2.1).

Given my ideas of power sharing so characteristic of a postmodern approach and my determination to negotiate the terms of the study with the participants, I was faced with a dilemma when the majority of the participants rejected the idea of negotiating their participation in the project with their children. I had to respect their point of view and I could relate to their "mode of tiredness". However, I was thinking about the idea of "agency". To have agency, "a person must 'take themselves up as a knowable, recognisable identity', who 'speak for themselves' and who 'accept responsibility for their actions'" (Nelson, Nicole, Mel & Kotzé 2000:122). I wondered in what way the modern humanist description of agency - that agency is a feature of "each sane, *adult* human being" (*italics mine*) and therefore excludes and marginalises children -

informed the mothers that they had to act on behalf of their children and protect them "for their own good" (Nelson et al 2000:122).

This dilemma raised an important issue regarding a participatory approach to practical theology and to a participatory research. I had to ask myself about inclusivity, "Could one ever be inclusive enough?" I had to ask myself about participation, "Could the participants decide who should not participate?" I had to ask myself about my own role, "Should I motivate who I wanted to be included, would that still be participatory research?"

### **6.3.8 Parent/professional relationship**

The parent/professional relationship surfaced in most of the group discussions. It appeared as though that was the cause of much pain and humiliation. By writing a letter to professionals, the group wanted to address the issues that concerned us, informing the professionals what we as mothers of differently abled children expected of them. We acknowledged our responsibility to inform them of our needs. We realised that they were, like us, caught up in and contaminated by cultural discourses that guided their actions. We hoped that through our letter, we could deconstruct some of these discourses. Through this act of resistance, some of us managed to deconstruct discourses regarding our relationship with professionals.

### **6.3.9 My son and I**

Finally, I would like to reflect on how my involvement in this journey impacted on the relationship between my son and me. Both of us felt that this journey drew us even closer. Henk appreciated my efforts to talk about "our" experience and my involvement in his world and his struggles. He did his best to assist me by sharing his ideas and thoughts about motherhood and ableism with me. Knowing that I cared that much, was a source of inspiration to him. He wrote in a letter:

*Thank you for writing about me. It made me feel special. If it had not been not for the \*book\*, Elisabeth, Lucia and Ian would not have corresponded with me. Their letters meant a lot to me, and I would like to think that I meant something to them.*

[\*After publication of *Telling Narratives* (Kotzé & Kotzé 2001), Elisabeth, Lucia and Ian corresponded with Henk in reaction to his introduction of himself. See paragraph 1.1, as well as Grobbelaar, Kotzé & Kotzé 2001:164-165]

However, through the sharing of information between us, Henk became acutely aware of how much I cared about him and how my sharing in his pain affected me. In an effort to spare my feelings, he became reluctant to share his experiences with me. Sometimes the pain of living as a differently abled person stifled the communication between us, but sometimes we had the courage to break through its silencing effect.

## **6.4 IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICAL THEOLOGY AND PASTORAL PRAXIS**

While formulating my commitment to this study, I entertained the question whether I would be able to contribute to the field of practical theology and pastoral praxis in co-researching the responsibility of practical theology and pastoral praxis to a small part of the community. As I was committed not to introduce topics for discussion at the group meetings, I never posed any direct questions in this regard. However, all the participants spoke freely about their faith that sustained them through difficult times. In the following section I reflect on pastoral guidance and ministering as well as the involvement of the faith community in the lives of families with differently abled members.

### **6.4.1 Pastoral guidance and ministering to families with differently abled members**

Although it was our faith that kept us going through all the hardships, certain religious beliefs served to confuse some of us. Moira felt burdened by the baptismal vows she had taken. She felt responsible for her son refusing to attend church services. Debbie experienced pastors as not always supportive or helpful. Rina, however, found that the church support group she was part of, helped her through difficult times. Suelene declined the financial assistance her church offered her, and asked for emotional support instead. Something the congregation did not offer.

Most of the participants' questions dealt with God's presence in suffering: "What is God trying to do with this pain, and my pain?" "How can they say that God only give good things to his children?" "Is this suffering God-sent punishment?" "What are the sins I committed?" "Why does God not heal my child?"

I wondered whether this research report would be able to inspire pastors and pastoral therapists to discover meaningful ways of interpreting Christian faith in relation to theodic issues as voiced in the questions above. I wondered whether it would be helpful if they could ask themselves the following questions: "How could we as pastors and pastoral therapists give 'permission' to free the individual in theodic transition to approach and address God in a more human style?" "How could we accompany the pilgrim on the journey from theodic darkness to theodic light?" "How could we, although we are always

ready to give encouragement, try not to indicate the road, but to accept the role of the spare wheel: to be available when needed?

Ikeler (1990:238) found that members of families with differently abled members "sometimes feel that their years are spent entirely in tightening, loosening or otherwise adjusting nuts and bolts". The experience of the group resonated with this idea. I wondered whether it would make a difference if the church consulted with families with differently abled children, and according to their needs introduced programmes that could offer assistance with transportation, domestic chores, respite care, information on financial assistance and parent support groups? I thought even a list of church members available to offer assistance, or whatever their needs might be, would be appreciated.

How could the pastor help families avoid isolation? Was the linking of parents with community organisations one way of accomplishing this? Could the pastor discuss isolation and stigmatisation with relatives and friends? Could the anguished hush surrounding impairment be broken through a special service to which the disabled family, their relatives and neighbours could be invited? What would the effect be when the service is followed by a meal and a "gathering of the clan" (Ikeler 1990:242) aimed at opening up communication between the family and their close relatives and friends?

What could preachers do to improve the communication process in the sermon? How could preachers be sensitised to the way the words and phrases they use constitute the lives of the congregation? Could the church create a platform from where the sermon could be discussed? Would sermon workshops enable the preacher to get to know the congregation's reactions, reservations, irritations and their grasp of the text (Pieterse 1999:102-103)?

I wondered whether this study could assist pastoral therapists to avoid the trap of capitalism, the desire to produce tangible results. Would therapists acknowledge the worth of witnessing the stories of the people who came to see them? How could latent voices be welcomed? Kaethe Weingarten (2001:120) argues "I try to give myself and/or the other the sense that we have all the time in the world to search for, try out, create, or bend language to serve the purpose of knowing and being known. The latent voice may speak the unspeakable, know the unknowable, if the voice feels welcomed."

#### **6.4.2 The faith community and ableism**

The group concluded that the insensitivity we as mothers of differently abled children, as well as our children, were experiencing, stemmed in most cases from ignorance rather than cruel intentions. Therefore,

we realised that we had to inform the public on what we would expect from them. I would like to believe that some of the actions we intended as a result of this research journey (see chapter 5), would be able to contribute to inform the community, the faith community and the broader society. We wanted to deconstruct some of the cultural and other ideas that were sustaining ableism in society.

I believe that ableism also causes pain to non-disabled people who are unprepared to deal with their own vulnerability and mortality (Weeber 1999:2). I also believe that the well-informed child is better able to accept a child who is different (Schnatterer 1993:40). A sermon on the topic of ableism could also offer parents the opportunity to discuss relevant issues with their children; especially those parents who are uncomfortable to introduce a topic like this.

I realised that maybe this project could be a drop in the ocean of doing theology when a colleague of a friend contacted me. He was part of a support group in his congregation and he was assigned to care for a family with differently abled children. He learned about this project through my friend and wanted information on the "do's" and "don'ts" from a group of insiders. We were privileged to invite him to a group session. Unfortunately, he fell ill before he could join us. However, we believe that this report would speak of the lives and experiences of families with disabilities.

#### **6.4.3 Agents in the mending of God's creation**

We invited two pastors of different congregations to the group discussions. Although small and perhaps insignificant, these were small steps towards a "just and participatory system geared to local needs" (Isherwood & McEwan 1993:61). Sharing information like this could contribute to the empowering of men and women to become agents in creating a more just society – agents in the mending of God's creation. The women involved in this project became involved in more than group discussions and in telling their stories. Their involvement strengthened me; it supported one another and most of all themselves. They have already indicated that the end of this project would not mean the end of their involvement. They planned to continue the journey, to keep on telling stories and to keep on being agents in the mending of God's creation.

For this vision and bravery I salute them.

Feminist theology recognises as one of its aims "the overcoming of old dichotomies and the ushering in of an understanding of pluralism which gives speech to the speechless, which empowers the powerless and which lets outsiders participate" (Isherwood & McEwan 1993:91). If this project could be able to contribute

in giving voice to the voiceless, in facilitating some transformation of the religious and church culture or in introducing new values and understandings, I would be honoured.

## **6.5 A CHALLENGE FOR PRACTICAL THEOLOGY**

The idea of praxis as central to practical theology needs reclaiming and reformulating from a feminist perspective that includes the voices of women and/or marginalised people. Constructing new inclusive models of preaching, including the lived experiences of women and their marginalised differently abled children could serve to widen the scope of practical theology.

The challenge is not one of “changing people’s ‘consciousness’ or what’s in their heads; but the political, economic and institutional regime of the production of truth” (Ackermann 1996:38). Engaging with stories alone, however, is not enough. We have to move from story to liberating praxis. The process of awareness begins by engaging in the mutual exchange of stories.

I agree with Ackermann (1996:49) when she says: “Theologians continue to be cartographers of changing contexts”. I hope that this study will not be read as the final answer to the curiosities that inspired it, but will rather serve to inspire us to return to the drawing board again and again to continue the praxis of mending the creation of God.

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**Gespreksgroep vir ma's wat voel hulle kinders het spesiale aandag  
nodig**

Ek is tans besig met nagraadse studies by UNISA. Die Titel van my navorsingsprojek is "Stories of mothers with differently abled children", en is by UNISA geregistreer vir MTh (Praktiese Teologie – met spesialisering in Pastorale Terapie). Dr Elmarie Kotzè is die aangewese studieleier, en Prof. Dirk Kotzè mede-supervisor.

Ek is self die ma van 'n seun wat sukkel met 'n spraakprobleem, en stel belang daarin om met ander ma's van "differently abled" kinders gesprekke te voer. (Onder "differently abled" sluit ek voorlopig kinders in wat as dagdromers, "nerds", wat leef in 'n fantasie-wêreld, kinders met aandaggebreksindroom of hiperaktiwiteit, of enigiets anders wat hulle "anders" maak as die meeste ander kinders, soos bv hakkel.)

As jy voel dat jy baat kan vind deur jou ervaring met 'n groep ander ma's te deel, skakel my asseblief by telefoonnommer 998 6732 of 083 271 6875

Ryna Grobbelaar

## **STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN**

### **INFORMATION SHEET FOR PARTICIPANTS**

Thank you for your interest in this project about the stories of mothers with differently abled children. By using the concepts differently abled children, I mean a young person or child with special needs, special ability or a disability. The terminology and purposes will be negotiated at our first group session. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, I thank you. If you decide not to take part, there will be no disadvantage to you of any kind.

#### **The aim of the project**

This project is being undertaken as part of the requirements for a Master's in Practical Theology – with specialisation in Pastoral Therapy. The aims of the project are to:

- (a) explore the influence of societal views, ideas and practices regarding motherhood, special abilities, special needs and disability in people's lives, focusing on mothers of differently abled children and how these discourses have affected/informed us;
- (b) explore the belief systems influencing the parent/professional relationship;
- (c) co-construct with participants alternative stories, questioning the societal views, ideas and practices that informed us and to re-tell our preferred mothering stories.

#### **Participants needed for the study**

Eight mothers of differently abled children will be included in the group discussions, telling their stories, how they experience being the mother of a differently abled child.

#### **What will be required of participants**

Should you agree to take part in this project, you will be asked to give consent for the information obtained during the group sessions to be used in the research project.

If you decide to take part in the project, you will be expected to attend 8 group sessions of about one and a half hours each, scheduled fortnightly. After each session, you will receive a summary of the session. You will be asked to make comments, corrections and/or provide feedback regarding the summary. Although the sessions will be held in either Afrikaans or English, the report will be written in English. Therefore, all the summaries as well as other correspondence will be in English. At your request, it can be translated into Afrikaans.

If you have participated in the study you will be requested to read the summary and comment on or change anything related to you or your family.

The differently abled young person or child will be requested to give permission for his/her mother to re-tell his/her story. The differently abled person will also be requested to give permission for the release of the information after he/she has read the summary of the sessions.

### **Free participation**

You are free to withdraw from the research project at any time you feel that you no longer want to take part, without any consequences to you.

### **Confidentiality**

The information obtained during the group sessions, will be discussed with my supervisor, and will be used in the project. With your prior consent, the group sessions will be audio taped. Should you choose not to have the sessions on audio-tape, I will make notes during the sessions. A summary of the sessions will be made available at the conclusion of the group sessions for your review. Your comments, corrections and/or feedback will be included in the final report.

The information collected during the project will be securely stored in a locked filing cabinet, and destroyed after conclusion of the project.

### **Results of the study**

Results of this project may be published. At your request, details will be distorted to ensure your anonymity. You will also have the choice to use your own name or a pseudonym of your own choice.

You are most welcome to request a copy of the results of the project should you wish.

### **Questions of participants**

Should you have any questions or concerns regarding the project, either now or in the future, please feel free to contact me:

Ryna Grobbelaar  
Tel: 998 6732  
Cell: 083 271 6875

Or my supervisor Elmarie Kotzé (D Litt et Phil) at the Institute for Therapeutic Development  
Tel: 460 6704



**STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN**

**CONSENT FORM FOR YOUNG PEOPLE AND CHILDREN**

I understand the aim of the study.

I understand that I will not be present during the group discussions of the mothers.

I understand that my mother will talk about me and me being "differently abled", and I give my consent that she may do this.

I understand that I will be given summaries of the discussions to read.

I know I can bring about changes or delete information that I do not want to be included in the report.

I choose the following name to be used for me during the discussions:  
Name to be used.....

I prefer to be known as:

- A person with a different ability
- A person with special needs
- A person with a disability
- \_\_\_\_\_
- \_\_\_\_\_

\_\_\_\_\_  
(Signature of child / young person)

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Name of child / young person in capital letters)

\_\_\_\_\_  
(Signature of witness)

**STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN**

**CONSENT FORM FOR PARTICIPANTS**

I have read the Information Sheet concerning the project and I understand what the project is all about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary
2. I am free to withdraw from the project at any time without any disadvantage
3. I am aware of what will happen to my personal information (including tape recordings) at the conclusion of the project, that the data will be destroyed at the conclusion of the project but any raw data on which the project depend will be retained for three years
4. I will receive no payment or compensation for participating in the study.
5. All personal information supplied by me will remain confidential throughout the project.
6. I am aware that Ryna's supervisor will read the material.

I am willing to participate in this research project.

\_\_\_\_\_  
(Signature of participant)

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Name of participant in capital letters)

\_\_\_\_\_  
(Signature of witness)

**STORIES OF MOTHERS WITH DIFFERENTLY ABLED CHILDREN**

**CONSENT FORM FOR RELEASE OF INFORMATION BY  
PARTICIPATING MOTHERS**

1. I have read the summary of the project.
2. I had the opportunity to bring about changes to that information, including suggestions, corrections or comments to summaries pertaining to my participation.
3. I agree for my suggestions, corrections or comments to be included in the research project.
4. I have read the final summary of the discussions and agree that this is an accurate and satisfactory account of the counselling process and I therefore give permission for this summary to be used in the research report.
5. I understand that the information obtained during the discussions may be written in an article format for publication. I also understand that should I decide that I do not wish for the information to be published I am able to withdraw my permission for this to occur at any stage of the participation in the project.

I hereby give my permission for information concerning myself, to be used in the written report of the project and in the publication. I understand that my confidentiality will be preserved throughout the study, in written report of the project and in the publication. I also understand that any information that may lead to my identification will not be used or included in the project report or publication.

I prefer the following name (either name or pseudonym) to be used in the research report or any other publication resulting from the project.

Name to be used.....

\_\_\_\_\_  
(Signature of participant)

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Name of participant in capital letters)

\_\_\_\_\_  
(Signature of witness)

**Lees Mark 10:35 - 45**

**Die volgende is 'n uittreksel uit Annelie Botes se nuwe boek "Raaiselkind".**

Die drie dae wat hulle by die Rooikruiskinderhospitaal was, was Alexander (seun van Dawid en Ingrid Dorfling) soos 'n dier in 'n vanghok daar in die hospitaalbed met die tralie kante. Wou aanmekaar oor die kante klouter om weg te kom. Die beddegoed met sy tande probeer skeur. Nie 'n krummel geëet nie. Hy het al remmende probeer losbreek uit die gespes en bande rondom hom en met gesperde oë gesoek na 'n wegkruipplek onder die bed.

Waaragtig, sy was van alle kragte ontdaan. Dawid het hom min gesteur. Die ure met 'n tydskrif in die ontvangslokaal omgesit. Sy moes die hardloop- en oppaswerk doen.

Net snags, wanneer die geraas in die hospitaal afgeplat het en slegs die nagliggies gebrand het, het Alexander soms stil geraak. Ingrid het haar hande deur die tralies gestee en oor sy ribbekassie gevryf. Kind van die donker.

Dagbreek. Personeel wat skofte ruil. Alexander sit gillende met sy bene deur die tralies en skop. Hy skree en klap die papbak uit die verpleegster se hand. Tol agteroor en begrawe sy kop onder die kussing.

Nog nooit het sy 'n mens so vreesbevange gesien soos daardie oggend toe hulle Alexander se kop in 'n masjien druk om 'n cat scan te doen nie. Sy wou hulle aan die ore gryp en skud tot hulle besef hulle woorde en instruksies is vir Alexander net 'n wasige warspul van klanke en brabbels. Maar niemand sou tog luister nie. Vir al wat sy omgee het, kon hulle hom in hand- en voetboeie sit en sy mond toeplak. Solank die hel vinnig klaarkry.

"Kom, Xander, Mamma sal by jou bly. Hulle gaan prentjies van jou kop neem." Asof Alexander verstaan het waarvan sy praat. Stoei net om af te klim. Die man wat die cat scan gedoen het, was kortgebaker. Gesê die kind is onbeheerbaar en sy moet by die koppenent staan en sy kop vashou. "Hy is bang," het sy verdedig. Die man het aangegaan asof hy haar nie hoor nie.

Rooikruiskinderhospitaal. Vir haar was dit asof almal net nommers en gevalle is. Niemand het tyd om stil te staan en te luister nie. Magtige mediese masjien wat rol en rol. Ratwerk van witgeklede mense, oorlaai met vol roosters. Niemand is ongeskik of onproffessioneel nie. Maar daar is min tyd vir genade. 'n Dokter is nie 'n sielkundige nie. 'n Verpleegster is nie 'n teedrinkvriendin nie.

Een of ander tyd moes sy gehuil het, want toe sy agterna haar hare in die kleedkamer gaan kam, het sy gesien haar oë was rooi en haar gesigvel opgepof.

Drie dae van louter hel was verby. Laai Alexander se hospitaalkoffer in die katebak, maak hom sit op die agtersitplek. Die pad huis toe het Alexander gebrak.

Sy kon nooit die mediese verslag uitlê nie. Dit was net 'n paar velle papier waarop 'n klomp onverstaanbare goed geskryf was. On-ontsyferbare mediese terme. Maar dit het nie vir haar gesê wat om met Alexander te doen nie. Nêrens was 'n finale diagnose aangedui nie. Die enigste paragraaf waarvan sy elke woord kon verstaan, was die finale konklusie. *Die hele gesin, maar veral mev Dorfling, moet sielkundige berading ontvang. Die moontlikheid om Alexander in 'n skool vir outisties-gestremde te plaas, of te laat institutionaliseer, moet ondersoek word.*

Outisties. Wat het dit beteken? Die verklarende woordeboek het gesê: *afsondering van die buitewêreld; uitsluitende belangstelling van die ego.* Sinlose spul woorde wat haar niks wyser maak. Sy het die dokter in die Kaap gebel maar kon niks meer uit hom kry nie.

Institutionalisering. Or haar dooie liggaam. Voor een heilige God, sy sou blindelings 'n ander pad soek. Al versaak die hele wêreld haar en Alexander uiteindelik, dit sou sy nie doen nie. Iewers, lewers moet daar iemand wees wat haar kon help.

1. Wat is Ingrid se grootste nood?
2. Ingrid sal van verskillende mense verskillende soort hulp vra. Watter soort hulp sal Ingrid van jou met jou unieke persoonlikheid en geslag vra?
3. Hoe sal jy vir Dawid help?
4. In Mark 10:38 vra Jesus: *"Kan julle die lydensbeker drink wat Ek drink...?"* In vers 39 sê Hy: *"Die beker wat Ek drink, sal julle drink..."* In verse 43 - 45 verduidelik Jesus wat dit beteken.
5. Om die "beker van Jesus te drink" is om jou lewe weg te lewe in diens van die nood van ander mense. Hoe drink ons ons bekere langs Dawid, Ingrid en Alexander?
6. Mark 10:35 - 45 is 'n teks waarin Jesus die essensiële lewenswyse, nie van enkelinge nie, maar van 'n geloofsgemeenskap of 'n gemeente uitspel. Navolging van Jesus is die navolging van vers 45.
7. Deel ons voldoende in mekaar se nood? Is ons verhoudinge veilig genoeg sodat ons ons nood met mekaar kan deel? Hoe kan ons dit veiliger maak?
8. Dink vir 'n oomblik na oor die stukke voor ons en oor ons gesprek. Voltooi dan die volgende sin: Dit is duidelik dat...